

Rejecting Stigma – Embracing ‘Living Flat’:  
Motivations for Resisting Breast Reconstruction and Prosthetic Breasts After Mastectomy

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## ABSTRACT

### Rejecting Stigma – Embracing ‘Living Flat’: Motivations for Resisting Breast Reconstruction and Prosthetic Breasts After Mastectomy

Laura Farnsworth

‘Going flat’ and ‘living flat’ following mastectomy for the treatment or prevention of breast cancer has become an emerging option that could be considered the zeitgeist of breast cancer culture in the 21st century. ‘Going flat’ is the informal term used when a woman does not undergo breast reconstruction after this breast removal surgery or has her reconstruction reversed for various reasons. Trending in popular and social media in the Western world, some social media platforms and mass media are increasingly sharing and reporting on these women’s lived experiences -- their narratives, photographs, filmed images and philosophy. What motivates the actions and behaviors of the women who are part of this growing subculture of mainstream breast cancer culture? Why are women deciding to say ‘no’ to breast reconstruction? Why do they also decide to forego wearing prosthetic breasts in public and ‘live flat’? What role do tattoos play in their ‘new normal’ body image? How are these women able to resist breast reconstruction as well as the wearing of prostheses and, in essence, reject Goffman’s very notion of spoiled identity-stigma itself? In effect, are these women using their agency to de-colonize the medically colonized female body -- thus normalizing ‘living flat’ as a respected post-mastectomy choice? Academic research that explores and endeavors to answer these questions has scarcely been undertaken, demonstrating an existing gap in the literature. By drawing on and analyzing data using thematic analysis from media interviews conducted with various media interviewees in multi-media -- published and available in the public domain on the Internet such as newspaper, magazine, organizational and dot.com websites, online videos, podcasts and documentary film -- this thesis aims to contribute to the growth of knowledge and research in this under-researched area.

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## Table of Contents

Preface .....	1
Introduction .....	2-5
Literature Review .....	5
flattoppers® and Flat Rebels .....	6-7
Restoring female ‘wholeness’ .....	7-8
Lorde, Kasper and Crompvoets .....	8-10
The Breast .....	11-13
Breast Cancer .....	14-17
Breast Cancer Surgery: Mastectomy .....	17-19
Paradigm Shift in Breast Cancer ‘Theory’ .....	19
Mastectomy Rates: Canada and the United States .....	20-22
Mastectomy Trending – ‘The Angelina Jolie Effect’ .....	23
Reconstruction Surgery: Canada and the United States .....	23-24
Breast Reconstruction: Advantages and Disadvantages .....	24-25
Breast Reconstruction Rates: Canada and the United States .....	25-26
Post-Mastectomy Options: Cross-sectional Survey .....	26-28
Breast Prostheses – ‘Artificial Breasts’ .....	28
Definition, description, history, and purpose .....	28-30
Wearing of Breast Prostheses: Lived Experiences .....	31-32
Prosthetic Breasts: To Wear or Not to Wear? .....	32-34
Sociocultural responses to mastectomy .....	34
Hegemonic-dominant Response .....	34-35
Dominant Body Norms .....	35-37
Norm of Body Part Replacement .....	37-39
Theoretical Framework .....	39
New Words .....	39-40
Introduction to Theories .....	40-41
Goffman, Swidler and Hochschild .....	41-43
Swidler Culture in Action .....	43-48
Application to phenomenon of ‘Living Flat’ .....	48
Goffman Social Stigma .....	48-53
Hochschild Emotional Labor .....	53-55
Fear Campaigns and Emotion Management .....	55-57
Methodological Framework .....	57-64

Media Interviews and Data Analysis .....	64
Women Who Underwent Reconstruction .....	64-69
From Implant to Explant .....	69-72
Reconstruction as a Routine Choice .....	72-73
Reconstruction Information for Women: Origins .....	74-75
Norm of Feminine Appearance .....	75-78
Mahalik et al. Conformity to Feminine Norms Inventory (CFNI) .....	78-81
Media Interviews and Data Analysis .....	82-88
Norm of Healthy Body Appearance .....	88-91
Health, Illness, and the Sick Role: Parsons .....	91-92
Sulik and the ‘She-ro’ .....	92-96
‘Going Flat’ and ‘Living Flat’ - New Breast Cancer Cultural Tool .....	96-97
Alternative Images: Critique of Reconstruction and Wearing EBPs .....	97
Resistance: Media Interviews and Data Analysis .....	97-113
Results, Discussion, and Conclusion .....	113-120
Limitations of this Research .....	120-122
Suggestions for Further Research .....	122-124
References .....	125-143

## List of Tables

<b>Table 1:</b> Crude and Adjusted Mastectomy Rates Among Women With Unilateral Invasive Breast Cancer, by Province, 2007-2008 to 2009-2010.....	20
<b>Table 2:</b> Reconstruction Among Women With Unilateral Invasive Breast Cancer Who Had a Mastectomy.....	26

## List of Figures

<b>Figure 1:</b> Screenshot from <i>New York Times</i> article: November 4, 2016 “The Women Who Showed Their Breast Cancer Scars” By Roni Rabin. Photographer: Béatrice de Géa for the <i>New York Times</i> .....	72
<b>Figure 2:</b> Screenshot still from Video: “Having a Mastectomy Tattoo” – Sue’s Story// One Minute Stories (2018). YouTube StanduptocancerUK.....	113

## Preface

I was motivated to write this thesis by my 2012 diagnosis of and subsequent experiences with breast cancer and mastectomy. On New Year's Day 2016, following a career in healthcare, education, a BA in Women's Studies and in my 66th year, I applied and was subsequently accepted to start a Master's degree in Sociology that fall.

One particular experience I had had the previous summer while living here in Montreal, drove my motivation more than any other. This event burnished my curiosity and spurred me on to find out and eventually try to explain to my self and others, why it had happened.

Surely I was not the only mastectomized woman who had experienced this? While walking my dog in my neighborhood, I had decided not to wear my prosthetic left breast, as I was in a hurry, and it was hot and humid. My sleeveless top revealed my un-camouflaged one-breastedness, for the first-ever time while in public. As I walked past two twentyish women relaxing on their street-level balcony, they suddenly shrieked, pointed at me, sniggered with hands covering their mouths and exclaimed "Oh mon Dieu!" to each other.

Once back in my apartment, I reflected on what had taken place. Why had these women reacted in such a manner? "Were they overtaken by fear – a kind of awkward, primal-reflexive fear, that they too could be at risk of losing their breasts and female self-identity to cancer, or even dying from it?" "Had my failure to hide my uni-breasted chest provoked their discomfort and if so, should I feel responsible for upsetting them?" So many questions flooded my mind. I wanted to know everything I could about this phenomenon, including the thoughts and feelings of other mastectomized women who may have had similar experiences.

Until the following year, when I read a *New York Times* article - "'Going Flat' After Breast Cancer" on October 31st 2016, I had not seen any woman in public without displaying a torso with two breast mounds; nor seen or heard in any media format at all, mastectomized women without prostheses (internal or external artificial breasts), showing the reality of their breastless chests and proudly speaking about all aspects of their lives in their newly-altered bodies.

On that day, I knew that my research would focus on this topic; a thesis providing a vehicle to address the research questions that flowed from it, such as: "What are the motivations of women in this 'going flat' and 'living flat' emerging sub-culture of mainstream breast cancer culture?" "How are these women able to resist breast reconstruction as well as the wearing of prostheses and, in essence, reject Goffman's very notion of spoiled identity-stigma itself?"



## Introduction

As of 2019, breast cancer continues to have a significant impact on societies in North America and around the world. This thesis examines the use of breast reconstruction and external prosthetic breasts in the context of female breast cancer and mastectomy. It undertakes a study into what ‘going flat’ (no breast reconstruction) after mastectomy, then ‘staying flat’ and ‘living flat’ (rejecting the wearing of prostheses) means, in cultural terms. This refusal to conceal the ‘flat-chestedness’ imposed upon women by breast amputation, is a behavior that is a relatively recent, nascent phenomenon when viewed as an expression of the breast cancer cultural movement.

The appearance of this phenomenon could be interpreted as some women taking up an oppositional stance of resistance to the dominant embedded cultural code assigned to women’s bodies – that of the dominant body norm of a feminine appearance -- that every woman should display a two-breasted body throughout her lifetime. The medical reasons for mastectomy (surgical removal of one or both breasts) being considered here are either a diagnosis of breast cancer or for prophylactic purposes when there is a significant threat of breast cancer. I will not be dealing with gender identity issues that might warrant this procedure in the scope of this thesis.

The choice of ‘going flat’ as a strategy directed toward achieving a sense of body ownership and agency will be a focus of this work. In North America and elsewhere, women are starting to turn away from the historical dominant breast amputation cancer discourse and binary choice proffered by the medical institutions – either undergo reconstruction or wear prostheses. I examine the choice of ‘living flat’ post-mastectomy in the context of contemporary cultural body norms, where pretending to have breasts is normalized and displaying any form of breastlessness is rejected. I explore and learn about women’s navigation of the dichotomous expectation that they either have their absent breasts reconstructed or wear external breast prostheses (false breasts) following mastectomy.

This either/or finite choice paradigm is being challenged by clusters of women who are manifesting a self-created option of a ‘third-choice’ – their decision ‘to do nothing’ following mastectomy surgery. They are doing nothing more than just to let their post-mastectomy bodies heal, and then choosing to live their lives in an un-camouflaged state of one or no-breastedness –

currently referred to as ‘living flat.’ This phenomenon demonstrates these women’s sense of agency in exploring “other avenues” so they can “begin to understand and accept the new materialities of their post-surgical bodies” and to “reconceptualize” their bodies as “normal, feminine and complete without two breasts” (Cromptvoets 2006, p. 148). This thesis will also explore the idea of resisting bodies, as in rejecting both internal implants and external prosthetic breasts. This resistance includes the notions of ‘staying flat’ and ‘living flat’ after ‘going flat.’ In popular North American culture, Hollywood film actress and breast cancer survivor Kathy Bates has publicly responded to her bilateral mastectomy without reconstruction, and her choice to stay flat and not wear breast prostheses by saying: “I don’t have breasts, so why do I have to pretend I do?” (*Toronto Sun*, 2017). The pioneering American flat positive advocacy and support group founded in 2013 -- *Flat and Fabulous* has a website, and social media closed group page of several thousand members. What are these women’s experiences with living this way? What is this about – sociologically speaking? What is the sociological significance of the appearance of *Flat and Fabulous*, along with similar others on the contemporary breast cancer cultural landscape?

Bates’ words echo those of a 1980’s feminist author Audre Lorde, who is one of several forerunners who have eschewed the wearing of breast prostheses and in doing so, refused to conceal their breast cancer and hide their post-mastectomy scars and chests. Along with Lorde, their resisting bodies have given a message of protest against the ‘biopolitics’ of breast cancer. Examples include New York artist JoAnne Motichka, known professionally as Matuschka; Darlene Betteley, Canadian-Ontarian activist; American feminist scholar Deena Metzger and Jo Spence, British photographer-feminist-activist. Why are women in survivorship without reconstruction post-mastectomy choosing to ‘live flat’? What motivates this choice? Is this taking the breast cancer movement to an entirely new level, as Rabin suggests: “The nascent movement to “go flat” after mastectomies challenges long-held assumptions about femininity and what it means to recover after breast cancer” (Rabin, 2016)?

This exploratory investigation leads to a myriad of wonderings and queries that emerge from such an undertaking: How do the sociological variables of age, ethnicity, gender and LGBTQ community members, and religion influence and impact decision-making and experience? How do the main social determinants of health impact decisions – that is – income and social status; employment and working conditions; education and literacy; childhood experiences; physical

environments; social supports and coping skills; healthy behaviors; access to health services; biology and endowment; gender; and culture (Government of Canada, 2018)?

What meanings do these women attach to ‘going flat’? Did medical-clinical, physiological, psycho-emotional or health care system reasons play a part in the decision to go flat? What tensions, conflicts, and conflicted emotions were experienced in their journeys? Were these conflicts mainly felt internally or was there an external component to them and if so, did they experience direct conflict with certain people, and if so, with whom? How much, if any, did dominant body norms exert compliance-to-conform pressure in terms of feeling it was easier to ‘give in’ and have reconstruction or wear prostheses? How has, or has being unbreasted or breastless impacted their identities as women? Do they feel they have a ‘spoiled identity’? In their experience, did they receive a message of ‘not being whole or feminine’ without breasts? If so, can they identify where this message originated – was it from an internal or external source?

My stance on this thesis topic and its companion issues is first and foremost located within neutral territory. This position comes from an overarching desire to be unbiased, as well as my attempt to provide an objective diversity of views. This point of departure is based on a basic human right dictum -- that every woman needs to exercise agency over her own body. In the socio-medical context that encompasses this thesis, in order to enact this agency, she needs to be given the full spectrum of post-mastectomy choices available. Currently these are: breast reconstruction, no reconstruction (‘go flat’) but wear external prosthetic breasts, or no reconstruction (‘go flat’) and not wear external prosthetic breasts (‘live flat’).

The media interviewees’ data reveals that the third option of ‘going flat’ and ‘living flat’ is not being offered as a routine standard of care by the majority of medical professionals. The literature in the breast cancer cultural canon also supports this finding (Lorde, 1980; Kasper, 1995; Gardner, 2000, 2002; Cromptvoets, 2006; Sulik, 2011; Offodile II & Lee, 2018). Offodile II & Lee, 2018 found that “shared decision-making” is a “critical component of the informed consent process” (p. 606). Women need all the facts before a true ‘decision’ can really take place – “The best decision takes into account evidence-based information about treatment options, the physician’s knowledge, and the patient’s preferences and values” (breastadvocateapp.com). In my aspiration for neutrality and to reflect diverse views, I also acknowledge that my own position necessarily informs my desire to make women’s struggles and protestations regarding the lack of a third option being offered, manifest.

The media interviewees' motivations for resisting reconstruction and the wearing of prosthetic breasts after mastectomy, otherwise known as 'going flat' and 'living flat,' varied widely. To summarize, they include – Regarding reconstruction: implants removed (explanted) on a permanent basis due to recurrent infections or adverse body reactions that made them feel unwell; simply not wanting to live with implants anymore; was not an option for medical-surgical reasons; physically active lifestyle initiated a desire to have a short surgical recovery period from mastectomy alone; reluctance to undergo multiple reconstruction surgeries with ensuing risk of complications; not wanting a reconstructed breast void of sensation; not wanting a “foreign body” placed inside the body; notions of authenticity along with not wanting to “pretend” to have breasts; not wanting to be “bullied” into having reconstruction versus wanting to have all medical decisions regarding the body to be theirs alone; simply “not wanting” to have reconstruction.

Regarding motivations for rejecting the wearing of external breast prostheses or EBP's – were as follows: not wanting anything hiding the scars as felt they had “embraced” their scars and they were now a part of them; had had chest tattoos and felt they had reclaimed their bodies for themselves – via employment of tattoos implied they did not need nor want EBP's hiding what they deemed as the “beauty” of their tattoos; not wanting to be “forced” to use “uncomfortable” EBP's and by extension and implication, not seeing EBP's as compatible with a physically active lifestyle; just not wanting to wear EBP's. Some women were motivated by online images of women with tattooed chests who had ‘gone flat’ and were living an uncompromising ‘flat life.’

## **Literature Review**

Very little scholarly attention to date has been paid to the issue of women's 'living flat' options post-mastectomy, yet this experience affects significant numbers of women across Canada and the United States, and indeed millions around the world. Academic research that explores and endeavors to explore the full spectrum of this issue has scarcely been undertaken, demonstrating an existing gap in the literature. I have been carrying out literature searches on this topic since the fall of 2016 and had encountered virtually no academic published texts dealing with this area of study. During that initial period, I encountered one piece bordering on the periphery of my topic -- a master's thesis that dealt with rejecting breast reconstruction and stigma management (see Joyce, 2014). Another quite early work by Feather, et al. (1989),

although not broaching the ‘flat’ topic, did deal with stigma and clothing of post-mastectomy women, which is an area that remains relevant today. The authors concluded that women should “cover” their “disfigurements” so they can avoid being stigmatized (Ibid, 1989).

A final literature search was carried out in June of 2019 on Google Scholar and Medline databases. On Google Scholar, the terms ‘mastectomy,’ ‘going flat,’ ‘flat,’ were used. On Medline ‘going flat’ was not a term option, so ‘mastectomy’ and ‘flat’ were used with a date limit of ten years, from 2009 to 2019. The Medline search yielded one relevant result published on-line in 2017, which was specific to breast cancer survivors who self-identified as sexual and gender minority (SGM): “Sexual and gender minority breast cancer patients choosing bilateral mastectomy without reconstruction: “I now have a body that fits me.” (Brown & McElroy, 2017). Almost 70 participants with an age range of 18-75 years completed a web-based survey. Most participants who identified as genderqueer or rejected gender labels used the term flattoppers® to describe themselves.

### **flattoppers® and Flat Rebels**

The survey results for “Gender and going flat” showed that most flattoppers® “felt more comfortable in their bodies after going flat” and others “that this treatment choice gave them a new sense of clarity about, or comfort with, their gender identity” (Ibid, pp 410-411). The term flattoppers® appears to refer more to ‘going flat’ and not having reconstruction, but does not seem to extend to ‘living flat’ in terms of not wearing prosthetic breasts. The specific variable of not wearing prostheses and living a completely ‘flat life’ publicly does not appear to have been studied as a separate variable in this research.

The Google Scholar results yielded the same Brown & McElroy article as Medline plus a Master’s Thesis dealing with designing clothing for double mastectomy clients who have ‘gone flat’ and are also ‘living flat’ in their public lives – “Apparel Design Process: Shifting the Basic Pattern Block into a New Framework to Fit the Demands of Post Double Mastectomy Women” (Gao, 2014); a paper presented at an intersectionality conference in 2016 “Ellen & The Real Girl: A Narrative Approach to Mastectomy, Reconstruction & ‘Going Flat’” (Ellen W. Klein, University of South Florida) and two articles published in academic publications: one is a New Zealand study that examined women’s posts in a breast cancer forum regarding their refusals of breast reconstruction. The researchers found that “Clothes and prosthetic breasts enabled forum

participants to pass as ‘healthy,’ ‘whole,’ and ‘recovered’” (La, et al., 2019). Only one three page article -- “Flat Rebels” (Whitaker, 2019) published in *Contexts* by the American Sociological Association, profiles the ‘going flat’ and ‘living flat’ phenomenon as one integrated behaviour. The article presents a concise, specific overview of all facets of these women’s lived experiences, as well as public displays of their non-reconstructed, non-prostheses wearing chests.

I found there were virtually no previous academic studies on ‘going flat’ and living a public and entirely ‘flat positive’ life. Given these results, it is concluded that existing research into ‘going flat’ and ‘living flat’ -- as in being a non-reconstructed and non-prostheses wearing woman is very limited, to essentially non-existent. More scholarly, rigorous research is needed for this topical area. Considering there is little to no previous academic systematic inquiry on the focus of my thesis research, as not much research is currently being produced on this topic yet, I turned to popular media sources such as on-line newspapers, magazines, and organizations for my initial material, to gain a baseline understanding of this phenomenon. From there, I engaged in ‘tracing and chasing’ to augment my sources database.

### **Breast ‘loss’ and restoring female ‘wholeness’ via surgical technologies**

Although a good deal of research has been done on breast cancer and the psychological, emotional, sexuality aspects of ‘breast loss’ and some on body image and identity post-mastectomy and breast reconstruction – an unbalanced number of studies have been done on the restoration of female ‘wholeness’ via the various surgical technologies of breast reconstruction. It appears incumbent on women who do reject breast construction to restore their ‘wholeness’ by using camouflaging clothing or prosthetic breasts. To leave themselves ‘flat’ and visibly ‘not whole’ in everyday public life, vis-à-vis social pressure to conform appears to be an overwhelming dilemma for most women (La, et al., 2019).

This current research situation points to the evident dearth of academic research that has explicitly focused on women’s post-mastectomy experiences of ‘going flat’ and living an entirely ‘flat positive’ life – having neither reconstruction nor wearing prosthetic breasts. A relatively small number of studies have explored unreconstructed women’s experiences navigating their post mastectomy worlds while wearing external breast prostheses. These will be discussed further on in this work. According to Gardner, “...few if any case studies examine the alternative of not

wearing a prosthesis” since “(the) option of living as a single-breasted woman is virtually ignored” (Gardner, 2000, pp 585, 587; Crompvoets, 2006, 2012).

Fallbjörk et al. concur with my finding. According to Fallbjörk et al. 's studies, contemporary research is mainly concerned with investigations of women's experiences or outcomes of different types of reconstruction surgeries, even in view of the fact that most women decide against having reconstructive surgery. Moreover, few meaningful, in-depth qualitative studies examine the concepts of sexuality, attractiveness, and femininity vis-à-vis unilateral or bilateral breast loss in delineated life stages (Fallbjörk et al., 2010, pp 175, 179).

One could postulate on a possible reason for this lack of studies; perhaps one influencing factor is that no significant monetary gain can be made from studying the woman who does not wear EBPs nor is a breast reconstruction patient. Which products and services could be promoted via marketing and advertising; how much profit can be made from a woman who is comfortable being breastless in the private and public domain, 24 hours a day, 365 days a year (Gardner, 2000, 2002; Crompvoets, 2006, 2012; Klawiter, 2008; Sulik, 2011, pp 341-342; Lorde, 1980; Batt, 1994).

### **Lorde, Kasper and Crompvoets**

Lorde's (1980) *The Cancer Journals* opened the door and paved the way for women to talk about breast cancer, environmental toxins, breast loss, prostheses and rejecting the wearing of a prosthetic breast: “When other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction, I find little support in the broader female environment for my rejection of what feels like a cosmetic sham. But I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other” (p. 16). Lorde demonstrated her dedication to being and appearing authentic both in the private and public domain, as she never accepted from her first post-surgical day, to wear a false breast to hide her amputated one when she wrote: “For not even the most skillful prosthesis in the world could undo the reality, or feel the way that my breast had felt, and either I would love my body one-breasted now, or remain forever alien to myself” (p. 44).

Another relatively early research project, although not explicitly dealing with the rejection of prostheses, did begin to deal with many salient topics vis-à-vis the social construction of breast loss itself. In the latter part of the 1980s, sociologist and women's health scholar Kasper

undertook a critical exploratory qualitative study on breast cancer, mastectomy and reconstruction. Of the 29 women in the study who had been diagnosed with breast cancer, 20 had mastectomies, nine lumpectomies, with 16 of the 20 mastectomized women undergoing breast reconstruction (in the late 1980s before the 1992 North American moratorium on silicone implants). Each woman interviewed was asked to talk at liberty about her own breast cancer experience and was encouraged to “tell your own story in your own words, in your own way” (Kasper, 1995, p. 203) Kasper’s research “... reveals that today’s culture creates a social context in which breast loss appears to have dire consequences for women and then provides the medical care to redress the loss it has helped create” (Ibid, p. 197; Zabjek, 2019). Zabjek’s reportings on breast loss addressed later in my thesis, describe this exact lived experience, just as Kasper’s study had concluded, whereby medical professionals predicted “dire consequences” of breast loss -- then also provide the solution to mitigate them, in the form of breast reconstruction.

Emerging themes of the psychosocial aspects and consequences of breast cancer on their health and lived lives culminated in several key findings from Kasper’s study demonstrating that: “... breast reconstruction is not essential to the resolution of a breast cancer crisis.” and that “...breast reconstruction fails to meet the expectations of these women with breast cancer because the women identify disjunctures between social expectation and their own interests in health and well-being” (Kasper, 1995, p. 197). One participant views her mastectomy as her “badge of courage” and reveals that the “flat side of her chest” does not present a “problem” for her; she “wears a prosthesis at work because she doesn’t want to discomfort people with the visible absence of a breast” (italics mine) (Ibid, p. 207). This situation speaks to the emotional labor that is often taken on by women with breast cancer and their motivations for hiding their mastectomized chests so that others are not ‘discomforted’ by them (Hochschild, 1983; Sulik, 2011).

In 2006, Cromptvoets published an influential book entitled *Breast Cancer and the Post-Surgical Body: Recovering the Self*. Through face to face interviews conducted in their homes, of a small sampling of Australian women who have undergone breast cancer surgery, she learns of their lived experiences and especially “how they (re)construct and ‘perform’ their post-surgical bodies” (Cromptvoets, 2006, p. 4).

Cromptvoets’ opening stance is premised on the notion that women who have had mastectomies “are offered no space by the dominant breast cancer culture, or by a broader sexist



society, to redefine their post-surgical bodies as complete or feminine without two matching breasts” (Ibid, p. 4; Mackenzie, 2007, p. 92). Her participants discuss their experiences with reconstruction and prostheses but not specifically about not wearing prosthetic breasts, except for one participant. She rejected wearing a prosthesis and was uni-breasted and “just flat on one side” for one year following her mastectomy. She was not motivated to wear an artificial breast for protecting “other people” from being “horrified.” However, after the year was over this woman underwent reconstruction but did not give any reason as to why (Cromptvoets, 2006, pp 117-118).

The author maintains that the post-surgical body of a woman with breast cancer has been commodified by a triumvirate consisting of prosthesis companies, the medical profession, and cancer organizations (Cromptvoets, 2006, p. 96). She suggests that prostheses act as a hindrance in the recovery process and, among other issues, impose upon women an expectation that they “perform their post-surgical body as incomplete and abnormal” (Ibid, p. 147).

Some of her conclusions reveal the fact that only two choices are traditionally, routinely, and prescriptively given by the triumvirate: undergo reconstruction or wear prostheses. Cromptvoets argues that encouragement of the idea that a woman could “reconceptualize her body as normal, feminine and complete without two breasts is utterly absent from breast cancer discourse” (Ibid, p.148). She asserts that “to do nothing” as a “third choice,” needs to be regarded as a viable ‘decision’ (Ibid, p. 148). She directly challenges, makes suggestions for the future, and critiques the:

“Mainstream breast cancer culture” as it “mobilizes dominant narratives of the post-surgical body reproducing it as unfeminine, desexualized and abnormal. There is virtually no space to develop the movement around acceptance of the mastectomized body. (...) Women who do not wear prostheses should be encouraged to be more visible within breast cancer culture, granting permission to other women to free themselves from the social obligation to ‘cover up.’ (...) (There are and should be alternatives such as developing a new framework) “...that situates the post-surgical body positively and locates femininity, sexuality and normalcy in things we do and feel, rather than the way we look, women can begin to conceptualize a new ‘whole’ self without two breasts” (Ibid, 146, 149, 150).

Several of Cromptvoets’ suggestions for the future made in 2006 appear to have been taken up by women engaged in the budding, contemporary ‘flat movement.’ The women who have created this zeitgeist trend, and the what, when, where, why, and how of their participation will be examined in this thesis.

## The Breast

One thing I've learned through all the years, is that a breast is a very subjective organ – and one woman can lose it and not think much more about it – another woman, it's *devastating* to lose it – and she will mourn for it for years.

Dr. Sheri Slezak, MD Plastic Surgeon, Greater Baltimore Medical Center,  
Associate Professor of Plastic Surgery, University of Maryland.  
Quoted from: *The Good Breast*, 2016

Breasts are the most visible sign of a woman's femininity, the signal of her sexuality. This culture fetishizes breasts. Subject to the logic of phallogentric domination of nature, their value, her value as a sexual being, appears in their measurement. Is she a B-cup or a C-cup? What matters is the look of them, how they measure up before the normalizing gaze. But male-dominated society tends not to think of a woman's breasts as hers. Woman is a natural territory; her breasts belong to others – her husband, her lover, her baby. It's hard to imagine a woman's breasts as her own, from her own point of view, to imagine their value apart from measurement and exchange.

Iris Marion Young  
"Breasted Experience: The Look and the Feeling," 2005

Breasts (mammary glands) in females have the distinction of being the only organ that is not fully formed as part of the body at birth. Although nipples with stem cells behind them are present, it takes the hormones of puberty to create the organ in its entirety (Love, 2019). Classified as an exocrine gland due to its capacity to produce and excrete a substance, in its case - milk (lactation), in females, specialized lobules make the milk and the milk ducts channel it to the outside via the nipple. Male breast anatomy almost mirrors that of the female, but does not include the milk-producing lobules, except in rare cases of abnormal male breast tissue (Erhan et al., 2006); male mammary glands do not undergo development and remain in a rudimentary state (Johns Hopkins, 2019; Rehfeld et al., 2017).

Besides being a lactation gland designed to nourish infants with breast milk, it is also an organ of sexual gratification: "For many women breasts are a multiple and fluid zone of deep pleasure..." (Young, 2005, p. 7). On a symbolic level, they function as a symbol of female sexuality, while also encompassing notions of female identity, femininity, and motherhood. In her 1970's early ground-breaking examination of the many facets of cultural construction that breasts have undergone in a Western society dominated by males, Young suggests that this sexual-motherhood duality brings about intense conflict for men and their "objectifying male

gaze,” when she refers to breasts’ “scandalous” quality -- because they have the power to “disrupt the border between motherhood and sexuality” (Ibid, p. 1).

An essential query Young has about breasts as she undertakes her feminist critique of the hegemonic discourses that encompasses them, is wondering how women can experience their breasts (and bodies) for and in relation to themselves, when women’s breasts have historically been constructed as objects already claimed as possessions, by males mainly in charge of Western societies and culture (Young, 2005; Yalom, 1997). She notes that for this to take place, the “objectifying male gaze” would need to be non-existent for women – in fact completely absent. To further facilitate that idea, it could be suggested that perhaps a collective women’s amnesia would need to occur, along with the suspension of reality by employing magical thinking, in order for this well-worn “gaze” to realize its absence from our socio-cultural world.

Although Young does not profess to uncover a “woman-centered breast experience,” she does hope to construct one by visualizing and giving voice to it in her writing– in essence, imagining the “breasted body” from scratch, exclusively invented by and for women. At the same time, she asserts that no matter what cultural oppressions women’s bodies encounter, a certain salvation comes from self love and, by extension, many women’s ability to love their bodies, identifying “their breasts as themselves, living their embodied experience at some distance from” (and in spite of) “the hard norms of the magazine gaze” (Ibid, p. 6).

Yalom reminds us that since historical records began, breasts have functioned as a “defining” female body part that has been “coded with both ‘good’ and ‘bad’ connotations” (1997, p. 4). Dichotomized into the “good” or “bad” breast can then be extrapolated into the marking with the stigmata of cancer and its sometimes required full amputation, as a modern-day “bad breast” – one with the markings of disease -- with the potential to maim, disfigure and kill the female body that houses it.

Dorothy E. Smith recounts, while trying to make sense of women’s experiences in society and culture, came upon a unique description by Rowbotham, of precisely what the ‘male gaze’ and androcentrism can do to women’s perceptions of themselves and their bodies. Rowbotham writes of being thirteen in 1967 and watching the adventures of the Beatles in their *Magical Mystery Tour* movie. When suddenly during their escapades, ‘the boys’ find themselves inside a strip-tease club: “I had caught myself going to watch another woman as if I were a man. I was

experiencing the situation of another woman stripping through men's eyes. I was being asked to desire myself by a film made by men" (Rowbotham cited by Smith, 1987, p. 52).

Rowbotham's experience speaks to Young's overarching concern that a gynocentric breast culture cannot exist in society yet, unless women set about consciously developing one by and for themselves, from their own experiences, visions, and imaginings. This creation could then spark women deciding to indeed take up dominion over their breasts (and bodies), and in doing so, decide how they want to live their breasted or breastless lives. Breast cancer may be a catalyst for how this concept can begin to be played out in current Western society.

Yalom confirms the validity of this notion when she states that "Today, it is the tragic reality of breast cancer that is bringing women into full possession of their breasts. They are learning, with the shock of life-threatening illness, that their breasts really are their own" (Yalom, 1997, p. 276). Yalom's ideation encompasses what women decide to do, not to do to or have done with their breasts – decisions made with or against the dominant socio-cultural and medical grain of dominant 'acceptable' breast cancer cultural practices.

Culturally speaking, Yalom's breast-ownership categories include: the sacred breast claimed by religion, the erotic breast claimed by the hetero-normative male world, the domestic breast claimed by the suckling infant and child, the political breast claimed by male politicians as the nurturing-life sustaining bosom of their created nationhoods, the commercialized breast claimed by male-dominated mass media -- fashion industry along with multiple other commerce industries, and the medical breast claimed by physicians and the domain of medicine.

In her categorization of the "medical breast," she reports that medical interest in the breast and its functions has clustered around two distinct poles -- its ability to maintain another human life via lactation or to cause death to a woman via breast cancer. Medical professionals since ancient times have been involved with caring for women's breasts, exclusively in these dual domains until relatively recently, when cosmetic surgery by plastic surgeons was added to the mix. Gradually, with the advent of animal milk pasteurization and human infant bottle-feeding, breast-feeding waned, and breast cancer disease became the focal point of medical practice in the twentieth century regarding the female breast (Yalom, 1997).

## **Breast Cancer Description, Statistics, Risk Factors: Canada, the United States, and International**

Cancer, also known as a malignancy or neoplasm, is essentially cells not developing normally. Once one gene-mutated non-normal cell replicates itself and divides, it can then turn into a group of abnormal cells (tumor) growing abnormally. When the body is unable to stop their proliferation, their growth cycle can eventually become out of control. When this situation occurs, it may lead to complete uncontrolled growth, resulting in the eventual overtaking of healthy, normal tissue. Cancerous tumors can grow into nearby tissues and spread to other parts of the body. Depending on the classification system used, there are more than 200 types of cancer (Canadian Cancer Society, 2019). Breast cancer makes up part of this number.

### **Breast Cancer**

The historical documented medical evidence of breast cancer dates back some 3,500 years to the Pyramid Age of ancient Egypt. Dozens of actual medical cases of malignant tumors in breasts were described and recorded by Egyptian surgeons on medical papyri (Lukong, 2017, p. 66). Hippocrates is credited with describing a variety of cancers using the Greek word for crab, which is *karkinos* or cancer in Latin, as he thought the tumors had a crab-like appearance (Ibid, p. 66; Cancer.org, 2019). When breast cancer reaches a never-treated, advanced state, its description is readily recognizable by modern medical professionals – even from thousands of years ago. There are also ancient texts from India that name “breast cancers” being treated with “surgical excision, cautery and arsenic compounds” (Lukong, 2017, p. 66; Maurer Foundation.Org, 2012). This treatment triad concept is still current today, and when described by American physician and celebrity breast surgeon Dr. Susan Love as “slash, burn and poison” – referring to surgery, radiation, and chemotherapy – it contributed to making her even more famous (Bolotin, 1997: New York Times.com). Although breast cancer can affect both female and male breast tissue, less than 1% of all breast cancers occur in men (Canadian Cancer Society, 2019).

There are two areas where breast cancer in women’s breasts commonly starts: in cells that line the milk ducts (ductal carcinoma) and in cells of the milk-producing lobules (lobular carcinoma). When ductal and lobular cancer cells stay in place within the milk ducts or lobules, it is said to be ‘in situ.’ However, if they begin to grow into surrounding tissues, they are considered to have become ‘invasive’ (Ibid). Cells may then potentially metastasize (spread) to other parts of the body. In the case of breast cancer, cells typically spread -- either locally to

surrounding tissues, or systemically via the lymph and circulatory systems, into the bones, liver, lungs, and brain (Ibid). Ultimately, it is usually the compromising of the function of vital organs that leads to death. A biopsy and microscopic examination of these cells are necessary for the pathologists to determine a definitive diagnosis as to type of breast cancer, grade level, and stage 0-IV categorization (Ibid).

As of 2019 cancer in general, and breast cancer specifically, continue to have a salient impact on North American societies and of those around the world. It continues to be a significant public health issue on a global scale, despite increased knowledge regarding its management, significant challenges persist (American Public Health Association, 2014; Lukong, 2017; National Cancer Institute, 2019). Breast cancer is the most commonly diagnosed cancer among Canadian and American women, and indeed among women worldwide (Canadian Cancer Society, 2019; American Cancer Society, 2019; World Health Organization, 2019).

The likelihood of Canadian females developing breast cancer during their lifetime is 1:8 or 12.5% versus any other form of malignancy. Women over 50 years of age account for 80% of the breast cancer cases diagnosed (Canadian Cancer Society, 2019; Government of Canada: Public Health Agency of Canada, 2016). In the United States, the lifetime risk is calculated as 12%, with 1 out of every 8 women expected to be diagnosed with breast cancer within her lifetime (American Cancer Society: Breast Cancer Facts & Figures 2015-2016, 14). The lifetime probability of Canadian women dying from breast cancer is 1 in 31 (Canadian Cancer Society, 2019).

In 2017, projected new cases of breast cancer in Canadian females were estimated at 26,300, with an average of 72 women in Canada diagnosed with breast cancer every day. Although lung cancer is the leading cause of cancer death for both males and females at about 26%, breast cancer is not far behind this, as the second most common cause of cancer death for Canadian females, with 13% of these mortalities attributed to it. According to the ASMR or age-standardized mortality rates regarding 2017 projected deaths from all cancers for Canada, 38,200 women were expected to die from all cancers, with 10,000 of those deaths from lung and bronchus malignancies, and 5,000 from breast cancer. On average, 14 Canadian women across the country died from breast cancer daily, according to the 2017 projections (Canadian Cancer Society, 2019; Canadian Cancer Statistics Advisory Committee 2017: 11, 20, 37-38, 42, 47, 62).

Adjusted for population, the American Cancer Society reports similar numbers, with an

estimated total of 331,530 new cases of diagnosed female breast cancer (combining in situ and invasive) projected for 2019. United States mortality rates from breast cancer for this same year are projected at close to 42,000 women; with only lung cancer, once again drawing a parallel with Canada, accounting for a higher number of cancer deaths in women. Present estimates put more than 3.1 million women in the United States as breast cancer survivors – those who have finished treatment and some who are currently undergoing it (American Cancer Society, 2019). For 2018, the World Health Organization reported global estimates of just over 2 million women diagnosed with breast cancer, with almost 630,000 who died from this disease (World Health Organization, 2019).

Due to breast cancer's distinction as the most prevalent cancer affecting women in North America as well as internationally, this disease has been deemed “a major public health concern” (American Public Health Association, 2014). Some diseases can be acute, chronic, life-threatening, or fatal. Breast cancer is a life-threatening disease that is sometimes fatal, and more recently (some attribute to treatment improvements) has the potential in some women to become a type of ‘chronic’ disease as well, where long-term treatment can take place and the term ‘living with metastatic breast cancer’ may apply (Mariotto et al., 2017).

According to major health organizations, definitive, specific risk factors for developing breast cancer remain complex and elusive in the majority of women diagnosed with the disease (Canadian Cancer Society, 2019; Public Health Agency of Canada, 2011; Centers for Disease Control and Prevention, 2019; World Health Organization, 2019). These national and international breast cancer and public health websites list several factors that show “convincing evidence” that they “increase your risk for breast cancer.” Some factors from their listings include getting older, personal history of breast cancer, family history of breast and other cancers, reproductive factors, genetic mutations, diet, dense breasts, exposure to ionizing radiation, taking hormones, drinking alcohol, obesity, physical inactivity, and smoking.

The Public Health Agency of Canada states that “Some researchers suspect that chemicals in our environment are increasing the risks of breast cancer for women. Although there is no evidence of a direct link between chemicals and breast cancer, we do not have all the answers about how chemicals affect our bodies” (Public Health Agency of Canada, (2009), 2011). Sometimes a woman may develop a breast malignancy without any identifiable risk factors (Canadian Cancer Society, 2019).

Some research is concluding that the main influencing factors for developing breast cancer are being a woman (due to having breast tissue and female hormones) and aging – as the majority of breast cancer occurs in women aged 50 to 69 years (Canadian Cancer Society, 2019; Public Health Agency of Canada, 2011; Centers for Disease Control and Prevention, 2019; World Health Organization, 2019). Dr. Lauren Schnaper, who has specialized in breast malignancies and breast surgery for the past several decades, is also the Director of the Greater Baltimore Medical Center’s breast care center. In the documentary film *The Good Breast* Dr. Schnaper is asked by a newly diagnosed breast cancer patient: “Can you tell me why I’ve got this? Is it just because I’m older?” Dr. Schnaper answers: “Well if I could tell you why you’ve got this, I would win the Nobel Prize” (The Good Breast, 2016: 1:18-1:43).

### **Breast Cancer Surgery: Mastectomy as a Primary Treatment**

Generally speaking, in the case of breast cancer and its treatment, tumor removal by way of breast cancer surgery is a priority, and usually, the first step taken. The two most typical-standard surgical options include undergoing breast-conserving surgery -- commonly referred to as BCS (also called lumpectomy or partial mastectomy), and mastectomy. BCS involves excision (cutting out) of the malignant tumor and a relatively small amount of non-affected breast tissue surrounding it, referred to as a margin, in an attempt to ensure that all the cancer cells have been removed (Canadian Breast Cancer Foundation, 2017; Canadian Cancer Society, 2019).

Mastectomy refers to the complete removal of the entire breast and nipple. There are three types of mastectomy, depending on how much tissue needs to be removed, typically dictated by the extent of tumor invasion. A simple (also referred to as a ‘total’) mastectomy is the removal of the complete breast and nipple, while a modified radical mastectomy goes a step further where the axillary (underarm) lymph nodes are removed, in addition to the nipple and breast tissue. The third type, pioneered at Johns Hopkins Hospital in the 1890s by American surgeons Halsted and Meyer, is the radical mastectomy. This procedure, which is rarely carried out today unless medically necessary, involves the removal of the nipple and all breast tissue, as well as the overlying skin, pectoral muscles, and all the axillary lymph nodes (Canadian Breast Cancer Foundation, 2017; Canadian Cancer Society, 2019).



## **Surgery as First Line of Defense: Milestones and Historical Contexts**

Benefitting from previously developed, evolved and improved breast cancer surgical techniques, availability of general anesthetics, vastly improved operating room contamination prevention (Lister 1867) and his pioneering of blood transfusions and surgical gloves, a new era of breast cancer surgery headed by American surgeon William S. Halsted in the 1880s led to the development of the Halsted radical mastectomy (Freeman et al., 2018; Travis, 2005).

Halsted's theory of how breast cancer behaved and spread was premised on his singular belief that it was a local-regional disease, which first originated in the breast itself and if not adequately surgically excised, would eventually spread to all levels of the breast anatomy – which included surrounding breast tissue, pectoral (chest) muscle, skin and lymph nodes. Halsted believed that cancer could be cured by surgery alone -- involving the sole employment of his radical mastectomy surgical technique – with “adequate local removal of the cancer” (American Cancer Society, 2019). According to Mitchinson, 2005, what is often obscured from the story of using Halsted's approach was that it was “designed predominantly as a curative procedure, the success of which was dependent on diagnosing the cancer early” (p. 404).

In the future, if that same breast cancer patient happened to develop cancer in another part of her body, Halsted deduced that it was unrelated to the original cancer in her breast; that it must be “a new process” that had occurred. In other words, he did not subscribe to the belief already held by some (British surgeon Stephen Paget, 1889), that breast cancer cells were like “seeds” that spread (metastasized) via the body's systemic blood circulation. Paget's “Seed and Soil Hypothesis” asserted that although some cancer cell “seeds” could travel to all body organs, they favored the “microenvironment of select organs...(implanting) in its suitable soil” (American Cancer Society, 2019, Langley et al., 2011, pp 1-3).

Halsted's technique entailed the surgical removal of all local-regional “suspected tissues” via “en bloc resection” -- in one continuous piece all together as a whole (Freeman et al, 2018, pp 311-312); the goal of his local-regional theory being not to disturb and thus ‘contaminate’ or spread any cancer cells around the immediate surgical-anatomical area. The resulting disfigurement and residual medical problems from this extensive surgery, such as “weakened arm function and disabling lymphedema” (permanent swelling of the affected arm), although affecting all aspects of women's quality of life, were seen as an unfortunate but unavoidable price to pay in order to save her life. When the surgical area was sutured together, the only tissue

remaining to cover the exposed ribs was a layer of skin (Mannu & Bhalerao, 2014, p E147). This procedure eventually became the universal standard treatment for breast cancer adopted by most surgeons, for almost a century (American Cancer Society, 2019) and was widely practiced in the USA and Canada well into the 1980s (Mannu & Bhalerao, 2014).

### **Paradigm Shift of Breast Cancer Theory: A Systemic Disease**

In the history of Western medicine, until slightly beyond the mid-twentieth century, surgical intervention remained the only treatment enacted for a diagnosis of breast cancer (Travis, 2005). Between 1959 and 1984, American cancer researcher Dr. Bernard Fisher focused on the biology of tumor metastasis. From their studies' results, he and his team developed an alternative theory for how breast cancer cells could spread throughout the body, resulting in their "systemic theory." Under this hypothesis based on the evidence they found, cancer cells were most likely already disseminated in the body systems by the time a breast cancer diagnosis is made (Ibid, 2005).

This belief profoundly impacted and was credited with revolutionizing surgical protocol for the remainder of the 20th century -- in that if some breast cancer cells were already circulating around the body when breast cancer was initially diagnosed, then "more expansive loco-regional therapy was unlikely to improve survival. (Consequently) ... less radical surgery was likely to result in similar outcomes to those obtained following radical mastectomy" (Travis, 2005, p. 1636). In other words, depending on the variables involved in each case, a lumpectomy along with some form of adjuvant therapy may be as effective as a radical mastectomy.

With Fisher et al.'s 1975, 1981 and 1985 (DeVita & Rosenberg, 2012) publications of the results of major studies conducted in the United States and Canada, came investigations into the efficacy of adjuvant therapy protocols – which are various treatments used before or after primary treatment such as lumpectomy or mastectomy breast surgery, to keep the cancer from returning. Adjuvant therapy can include therapies such as the use of radiation, chemotherapy, hormonal treatment, and antibody therapy (Mayo Clinic.org, 2019). Eventually, almost within the next decade, the Halsted radical mastectomy was rendered "an operation of historical interest only" (Cotlar et al., 2003, p. 335).

## Mastectomy Rates: Canada and the United States

According to reports published in 2012 by the Canadian Institute for Health Information (CIHI) and the Canadian Partnership Against Cancer, mastectomy rates do not share a common percentage trend throughout Canada. The study encompassed data from about 22,000 Canadian women per year, diagnosed with breast cancer, compiled over three years; tracking their surgical progress for a time frame of one year – beginning with the women’s initial surgery date. Results showed that crude mastectomy rates for breast cancer ranged from 26% of patients in Quebec to 69% of patients in Newfoundland and Labrador (Breast Cancer Surgery in Canada, 2012, p x) with a national adjusted mastectomy rate of 44% -- controlled for age group, neighborhood income and travel time to nearest cancer centre [Table 1 (Source: labeled Table E2)].

Table 1: Crude and Adjusted Mastectomy Rates Among Women With Unilateral Invasive Breast Cancer, by Province, 2007-2008 to 2009-2010.

<b>Table E2: Crude and Adjusted Mastectomy Rates Among Women With Unilateral Invasive Breast Cancer, by Province, 2007–2008 to 2009–2010</b>			
	<b>Crude Rate</b>	<b>Adjusted Rate</b>	<b>Canada</b>
<b>B.C.</b>	46%	45%	44%
<b>Alta.</b>	56%	56%	44%
<b>Sask.</b>	65%	60%	44%
<b>Man.</b>	36%	35%	44%
<b>Ont.</b>	38%	39%	44%
<b>N.B.</b>	47%	41%	44%
<b>N.S.</b>	56%	52%	44%
<b>P.E.I.</b>	59%	56%	44%
<b>N.L.</b>	69%	61%	44%

### Notes

Data relates to patients who received their index procedure between 2007–2008 and 2009–2010.

Excludes data for residents of the three territories and Quebec.

Adjusted rates control for age group, neighbourhood income quintile and travel time to closest cancer centre.

Crude rates in this table differ from those presented in Figure 1 due to calculations of denominators for each province included in the analysis.

### Sources

Hospital Morbidity Database and National Ambulatory Care Reporting System, Canadian Institute for Health Information; Alberta Ambulatory Care Reporting System, Alberta Health and Wellness.

Breast Cancer Surgery in Canada, 2012 (2007–2008 to 2009–2010) (p. 42)

Through this Canadian study, it was revealed that several influencing factors were at play in terms of what could have the potential to affect these rates. Variables such as age, income and travel time to the nearest radiation facility came out in front as the strongest influencers on Canadian mastectomy rates: Age influences a woman’s surgical procedure choice in multiple ways -- such as her perceptions of the risk factors, body image esteem at this particular time in her life, and overall attitudes toward radiation and breast reconstruction. Among women with invasive breast cancer, 44% chose mastectomy when they were aged 18 to 49. However,

mastectomy rates declined to 35% when women reached the age category of 50 to 69 years, and then rose once again to 45% at age 70 and older, respectively (Breast Cancer Surgery in Canada, 2012, pp 7-9).

Additionally, the authors postulated that perhaps tumor characteristics and the availability of breast reconstruction in their geographical area could also offer some explanation of these numbers. Regarding socio-economics and income, women living in the lowest end of the income spectrum had “significantly higher rates of mastectomy than women in more affluent ones” (Breast Cancer Surgery in Canada, 2012, xi).

The report theorizes that the reasons for this could include factors such as loss of income due to treatment duration (so mastectomy is chosen over BCS and a lengthy, daily radiation treatment schedule), and levels of health literacy that can ultimately influence this group’s “health care decision-making” (Breast Cancer Surgery in Canada, 2012, p. 9). In the case of travel time to a cancer center with a radiation facility, logistically speaking, it was discovered that this factored into this cohort’s mastectomy decision-making as well. Radiation treatment is not available in every cancer center across Canada, and if BCS with a post-op protocol of several weeks of daily post-surgical radiation therapy is being considered, then variables such as travel time, time of year, weather and road conditions, transportation, economic resources, and childcare all need to be dealt with. If one or more of these result in insurmountable issues, then the more likely mastectomy will be chosen, which usually does not require post-op radiation (Ibid. p. 10).

The overall rate of mastectomy in the United States was reported as almost 41% in the year 2000, with an apparent decrease to 37% in 2006, (Jatoi, 2015, p. 387), rising up to 38.4% in 2008 (Klem, 2013, p. 133), indicating that BCS lumpectomy remained the preferred option (Habermann et al., 2010). As interpreted by Dr. Jatoi, and considered side by side, “more women were choosing lumpectomy in the United States, but among those who chose mastectomy, CPM was increasingly becoming the preferred option” (Jatoi, (2015), p. 387; Habermann et al., 2010). As reported by Habermann et al., between 2000 to 2006, CPM rates increased by more than 150% since 1998 for patients who had unilateral breast cancer. The topic of CPM or contralateral prophylactic mastectomy and its implications will be discussed at length in subsequent pages of this text.

Initially, most women will be diagnosed with breast cancer in one breast (unilateral), while the unaffected, opposite breast (termed the contralateral breast) after testing to be negative for

cancer, will be considered cancer-free at that time. British researchers in surgery-histopathology, Kollias et al. found a contralateral breast cancer incidence (cancer diagnosed in the opposite breast) of 5.6% at ten years and almost 10% at fifteen years (Kollias et al., 2001). This data gives the potential for eventual bilateral mastectomies to be happening over time in these 5 to 10% of cases, although each breast receives a cancer diagnosis and is removed separately on a different date.

Bearing this in mind, the next natural question to arise is: “How often do Canadian women undergo a contralateral prophylactic (preventive) mastectomy?” and, as a result, have both breasts surgically removed in one operation, known as a bilateral mastectomy and become “breast-less”?

Regarding contralateral prophylactic mastectomy (CPM), as per the Breast Cancer Surgery in Canada study, its authors put forth that the empirical-clinical indications for such a strategic surgery involve only those women who are at very high risk for contralateral disease. Quantitatively, women who are in this unique category are relatively small in number (for example, those with BRCA1-2 gene mutations and those with a history of childhood/adolescence chest irradiation), and “...its use is controversial because there is little evidence of its benefits in terms of long-term survival for women who are not at high risk for contralateral disease. Concerns have arisen, especially in the U.S., that women without clear indications are opting for CPM” (Breast Cancer Surgery in Canada, 2012, xi).

The rate for Canadian women deciding on CPM after choosing mastectomy surgery for unilateral invasive breast malignancy between 2007-2008 and 2009-2010 was 6%. In other words, 6% of this cohort underwent a bilateral mastectomy and had both breasts surgically removed simultaneously, when only one breast had been diagnosed with cancer at the time of surgery (Ibid, xi).

A 2003 published estimate from the U.S. of CPM’s of some American women making this same decision, was almost twice as high, at 11% (Ibid, xi). A California 2011 study revealed that the groups most likely to choose CPM versus others included Caucasian women younger than forty, who held private insurance and had been patients at a National Cancer Institute-designated cancer center (Jatoi, 2015, pp 387-88).

## **Mastectomy Trending and ‘The Angelina Jolie Effect’**

Although space constraints preclude an in-depth discussion of this topic, a mention here needs to be made regarding an upswing in the mastectomy trend, in what has come to be known as the ‘Angelina Jolie Effect.’ This phrase refers to bilateral risk-reducing mastectomy (BRRM) as a result of Ms. Jolie being tested and diagnosed in 2013, as a carrier of the “maternally inherited pathogenic BRCA1 gene mutation” and based on her positive test results, her subsequent decision to undergo a BRRM (Evans et al., 2015). This British study undertaken by Evans et al. discovered that referrals for medical consultation (including women with and without known genetic risk factor histories), mutation-carrier testing, and subsequent BRRM’s based upon positive results for BRCA1/2 and other pathogenic genetic mutations, all increased by 2.5-fold between 2013-2015 (Evans et al., 2015). A question for further study would be to see how this ‘effect’ impacted BRRM’s as well as CPM’s in Canada and the United States vis-à-vis the rates of bilateral breast reconstruction as well as the breastless ‘going flat’ movement.

## **Reconstruction Surgery following mastectomy: Canada and the United States**

Breast reconstruction refers to “reconstructing” – rebuilding or recreating the surgically removed breast gland ‘form’ -- with either a saline or silicone implant, tissue from another part of the woman’s own body (autologous), or a combination of the two (American Cancer Society: Breast Cancer Facts & Figures 2017-2018, pp 25-26). It is surgery usually performed by a plastic surgeon, where the main goal is to rebuild the physical-external shape of the breast; however, the physiological aspects, such as sensation and sexual arousal, are not usually expected to be restored. A type of breast “mound” is created, which “...restores a more normal-looking body when clothed... This operation is about giving women a normal look with clothes on” (BC Cancer Agency, 2018).

There are a variety of variables that may influence and constrain a woman’s breast reconstruction choice outcome. In other words, a woman who undergoes mastectomy and envisions having her breasts reconstructed -- but it does not happen for her. Some of these may include lack of breast reconstruction information; medical-surgical reasons and risk factors unique to her case, low income and non-urban residence, issues regarding time off from employment, financial, travel-logistical issues in rural areas, access to available plastic surgeons

in her area, access to reconstruction facilities and availability of operating room time (Platt et al., 2011, pp 2110-2115; Breast Cancer Surgery in Canada, 2007-2008 to 2009-2010 pp 19, 27).

Ultimately, Platt et al. state that the ‘optimal rate’ of breast reconstruction is not currently known for any jurisdiction in Canada, and concurrently, *little is really known about the influencing factors on the rate of breast reconstruction* or “the reasons for its underuse” (Ibid, p. 2114, Italics mine).

### **Advantages/Disadvantages of Breast Reconstruction:**

The University of Michigan Faculty of Plastic Surgery Specializing in Mastectomy Reconstruction has created a 30-page booklet titled The Decision Guide to Breast Reconstruction. The document meticulously lays out a pro/con-advantages/disadvantages approach to a woman’s post-mastectomy, breast reconstruction decision process such as:

Breast reconstruction may help you to feel better about your body: you may feel more ‘normal,’ ‘balanced,’ and feminine. It may also help you to be able to wear more kinds of clothes with convenience and comfort. Only you can decide whether the mental and physical benefits of having a new breast are worth the costs of having the surgery.

#### Advantages of Breast Reconstruction:

You may feel more ‘balanced,’ in terms of both breast weight and looks.

Your body may feel more ‘normal,’ in and out of your clothes.

You may be able to wear more kinds of clothes, possibly even low cut clothes like tank tops and bathing suits.

You may feel more feminine and attractive.

You may not be reminded of the cancer by having only one breast.

#### Disadvantages of Breast Reconstruction:

Regardless of the type of reconstruction you have, you will need more surgery, with all of the inconvenience and potential problems that come with it.

You may need more time to heal.

You may need to take more time off from work or from your family responsibilities.

There may be more scars.

There are risks with the reconstruction surgery, including infection, swelling, or delayed healing.

If you do not have insurance, it may be costly.

You won't know how the new breast will look until it is finished.

The new breast, no matter how good it is, will never exactly match your natural breast. (Natural breasts are almost never exactly the same, either!) Also, the reconstructed breast will not duplicate or look precisely the same as the breast which was removed. In rare cases, there may be problems that can occur years after the reconstruction, like infections, hernias, or breast implant complications (Brown et al., n.d).

Although the messaging contained in this passage appears to be neutral, fact-based ‘medical’ information designed to assist women in their decision-making process, several biases toward body image and femininity tropes are embedded in the text, such as “feel better about your body;” “feel more” -- ‘normal,’ ‘balanced;’ feminine; attractive; having reconstruction will leave no reminder of having cancer” (Ibid, n.d.). Further in this work, these same variables are addressed by the media interviewees through their responses on these topics; addressing some of them as breast cancer culture mythology that is ultimately dispelled as such.

### **Breast Reconstruction Rates: Canada and the United States**

Reported rates of breast reconstruction (either immediate or delayed) in the United States vary widely (depending on the raw data sources), but some population and hospital-based studies cited by Platt et al. put the U.S. rate from 1985-1990 at 3.4%, with a rise up to a level of 42% in 1997-2002. The American Cancer Society reports breast reconstruction at 12% in 1998, rising to 36% in 2011, while the U.S. rate given by Butler et al. (2016), for immediate breast reconstruction in that country is 40% in the same year (2015).

The United States Women’s Health and Cancer Rights Act in force since 1998 mandates groups’ health plans, insurance companies, Medicaid, Medicare, and other organizations covering mastectomy surgery to pay for reconstructive surgery (American Cancer Society: Breast Cancer Facts & Figures 2017-2018, pp 25-26). However, when these are compared to the case of Canadian rates, Platt et al. report that Canada’s have “historically been low” and that “...compared with other jurisdictions, it is unlikely that our current practice has achieved an optimal rate.” In the case of women who need to choose between breast-conserving (lumpectomy) or mastectomy, they may be demonstrating a preference for mastectomy with reconstruction in order to avoid radiation and “the stigmata associated with having a mastectomy defect” (Platt et al., 2011, pp 2109, 2113 & 2114).

The Breast Cancer Surgery in Canada, 2007-2008 to 2009-2010 study estimated that 9% of the cohort of Canadian women who received a mastectomy for unilateral invasive breast cancer had breast reconstruction performed – with 7% having immediate and 2% receiving delayed, following surgical removal of the involved breast [Table 2 (Source labeled: “Table 3”)]. The Canadian Cancer Society reports that of an estimated 26,200 women diagnosed with breast cancer in 2017, about 6,000 undergo mastectomy annually. Fewer than 1 in 5 or (16% of



Canadian women have breast reconstruction surgery after mastectomy. The CCS compares the United States reconstruction rate at 38% reporting that Canada's is less than half that number (Canadian Cancer Society, 2017, 2019).

Table 2: Reconstruction Among Women With Unilateral Invasive Breast Cancer Who Had a Mastectomy

<b>Table 3: Reconstruction Among Women With Unilateral Invasive Breast Cancer Who Had a Mastectomy</b>					
		<b>2007–2008</b>	<b>2008–2009</b>	<b>2009–2010</b>	<b>Total</b>
<b>Mastectomy</b>	<b>Total</b>	<b>5,892</b>	<b>6,182</b>	<b>6,301</b>	<b>18,375</b>
<b>Reconstruction</b>	<b>Immediate</b>	<b>370</b>	<b>410</b>	<b>416</b>	<b>1,196</b>
	<b>Delayed</b>	<b>123</b>	<b>128</b>	<b>124</b>	<b>375</b>
	<b>Any Reconstruction</b>	<b>493 (8%)</b>	<b>538 (9%)</b>	<b>540 (9%)</b>	<b>1,571 (9%)</b>

**Note**

Data relates to patients who received their index procedure between 2007–2008 and 2009–2010.

**Sources**

Hospital Morbidity Database and National Ambulatory Care Reporting System, Canadian Institute for Health Information; Alberta Ambulatory Care Reporting System, Alberta Health and Wellness.

**Breast Cancer Surgery in Canada, 2012 (2007–2008 to 2009–2010) (p 18)**

Many women who have undergone breast reconstruction are shocked, disappointed, and feel betrayed when, following their recovery, they realize that their breasts are void of sensation and have become permanently numb. They are angry that they were not given these facts prior to surgery (Rabin, 2017). Wesleyan University professor of gender and sexuality Victoria Pitts-Taylor has highlighted this in saying that “The focus on how breasts look and feel to other people, rather than how they feel to the patient, speaks volumes to the fact that women are still largely judged by their appearance. There’s such a strong cultural gaze at women’s breasts – It does raise the question: Who is breast reconstruction for?” (Quoted by Rabin, 2017).

**Post-Mastectomy Options: Cross-sectional Survey of Breast Cancer Agencies, non-profit organizations, societies, associations, and government health websites**

Of the Canadian and American breast cancer agency, non-profit organization, society, association and governmental websites that I have reviewed, to date I have discovered several that present an either-or-two-choice dichotomy for post-mastectomy options of living with one breast or being breastless. There are others, however, that provide a more balanced array of information on suggested choices for post-mastectomy women.

Further focus on these websites yields the following examples from this sampling: the BC Cancer Agency has a heading titled “Reconstruction or prosthesis” but ultimately does not

mention nor discuss anything on prosthesis, nor any other options besides reconstruction. The Canadian Cancer Society has a section titled “Reconstruction and Prostheses.” Three options are presented with a description of each: Breast reconstruction, breast prosthesis, and choosing to stay flat. The American Breast Cancer Foundation website states that it is a national charity providing educational resources and other services to underserved and uninsured individuals. It has two pages – one with the heading “Reconstructive Surgery” and another with “Breast Reconstruction Awareness USA.” There is no other information on its website regarding any other options after mastectomy -- only reconstruction is presented. The “Awareness” webpage goes on to say that their “Awareness campaign” is sponsored by the *American Society of Plastic Surgeons* and The Plastic Surgery Foundation, with financial support through corporations, institutions, private practices and individuals (American Breast Cancer Foundation, 2019).

While in contrast, the Canadian Breast Cancer Foundation’s site, although it also has a heading titled “Breast Reconstruction and Prosthesis,” has written an extensive discussion on breast prosthesis and at the same time highlighting the issue of choice for every woman: “Whether you choose breast reconstruction surgery, prosthesis, or not to take any action after having breast cancer surgery, it’s important...feel good about yourself.” and “The choice to wear a prosthesis is yours” (Canadian Breast Cancer Foundation, 2017).

The National Breast Cancer Foundation Inc. is a US charity with a webpage category heading “Breast Reconstruction.” Selecting this page gives the reader information on breast reconstruction along with a video and diagrams on the various types of reconstruction procedures. However, topics such as “Are There Any Alternatives to Breast Reconstruction Surgery?” are also discussed – naming “a removable prosthetic breast that is worn in the bra” as one alternative. At the end of the page, a clear message of choice is given:

Whether you undergo breast reconstruction, wear a prosthetic breast, or choose to simply embrace the changes you have experienced by allowing the breast removal to remain obvious, you should feel free to make whatever decision is right for you. The goal is to prevent the discomfort of unwanted change, while enabling you to accept what has occurred and continue on with your life.

(National Breast Cancer Foundation: National Breast Cancer.org, 2017)

The American Cancer Society’s site has a webpage with the heading “Breast Reconstruction Alternatives: What if I choose not to get breast reconstruction?” Here it is stated that there are two main options for women who have chosen not to have breast reconstruction: 1. Using a prosthesis – also known as a breast form, inside their bra or attached to their body, worn under

their clothes and 2. Going flat – not wearing a breast form. The concept of “going flat” has now been formally introduced; a relatively extensive discussion on all aspects of how to “go flat” follows (American Cancer Society, 2017).

## **BREAST PROSTHESES – ‘Artificial Breasts’**

### **Breast Prostheses: Definition, description, history, and purpose**

#### **The wearing of breast prostheses: lived experiences**

#### **Prosthetic Breasts: To Wear or Not to Wear?**

### **Breast Prostheses: Definition, description, and history**

The term prosthesis (singular) and prostheses (plural) refers to an artificial body part or parts. The term prosthetics describes the scientific and technological processes used to create these human-made devices and body parts. The term ‘prosthetic’ can also be used as a descriptor adjective – such as ‘prosthetic’ breast (www.amputee-coalition.org, 2019; www.advantagepo.com, 2019).

What is a breast prosthesis? A breast prosthesis is an artificial, ‘substitute’ or ‘false’ breast worn externally. Particularly in research material, they are also sometimes referred to and abbreviated as ‘EBP’s’ – meaning External Breast Prostheses. A breast prosthesis, which is also known as a prosthetic breast or breast form, is a breast-shaped form worn inside a bra pocket (or attached to the chest skin with a special-purpose adhesive) to replicate the natural shape of a breast. Although they may be made from an array of materials and contain a variety of fillings such as foam, fiberfill, micro-beads, silicone or cotton, most are made from soft silicone gel encased in a thin film (www.cancer.ca, 2019; www.cancer.net, 2019; www.breastcancercare.org.uk, 2019).

According to the Canadian Cancer Society, breast prostheses can be used on a temporary or permanent basis. One purpose of wearing an artificial breast form would be to give “a breast a more natural shape after mastectomy or breast-conserving surgery.” However, the organization acknowledges that any decision regarding their use is “very personal” and “is based on your feelings, desires, lifestyle, and other factors” (www.cancer.ca, 2019).

### **History of Breast Prostheses**

The first patents for aesthetic purposed prosthetic breast forms were filed in the United States as early as 1873, with specific and distinct medical applications for them happening by 1919.

Attributed mainly to Halsted's standardized radical mastectomy as the only acceptable gold standard treatment for breast cancer, more and more women became survivors of the diagnosis. Due to the extensive loss of tissue, lymph nodes and pectoral muscle that took place with this surgery, "an expanding market emerged for women who wanted to disguise the results" of this disfiguring surgery by wearing "breast forms" (prosthetic 'artificial' breasts) Gardner, 2002, p. 102).

Gardner's historical research reveals the cultural thinking of the day from descriptions gleaned from inventors' patent office applications, whereby a '... surgical bust form offered a ...' "convenient and comfortable substitute for the bust of a woman, which has been removed by surgical operation, and which will relieve the flattened appearance caused by the operation and will reproduce the exact shape of the amputated part" (Gardner, 2002, p. 102). In revealing these historical contexts, Gardner asserts that they help to explain her belief that "Historically inventors have conflated the aesthetic and medical application of the breast form" (Ibid, p. 103).

Gardner's work analyzes "the breast prosthesis industry as a beauty business." As the number of women diagnosed with breast cancer rose, "capitalist ventures emerged to meet the demands of those affected by the disease." Along with the more abundant selection of prosthetic breasts produced by these companies, came a clear message that "the scars from surgery should be hidden from public view." The author considers "the use of breast prostheses as a contested part of cancer recovery," the breast prostheses industry's response to buyers' demands and how it "created a niche for itself within the 'healing process,' and capitalized on notions of feminine beauty" (Gardner, 2000, p. 565). This viewpoint has been taken up and synthesized by many others, which will be discussed further in this section.

This assertion could be seen to be upheld to the present day, whereby post-mastectomy, women are routinely given interim external light-weight breast forms following their surgery by medical health care personnel or volunteers, with the mantra that wearing them 'will help with their healing' – adding a layer of medical necessity to the act. The same can be said for internal breast forms-prostheses (implants), when doctors discuss them pre-mastectomy, often stating that having them implanted immediately after removal of their breasts will greatly assist with 'the healing process' and their 'return to normalcy' (Lorde, 1980; Kasper, 1995; Gardner, 2000, 2002; Young, 2005; Cromptvoets, 2006; Sulik, 2011; Wegenstein, 2016; Offodile II & Lee, 2018).

### **Purpose of External Breast Prostheses (EBP)**

The purpose of an EBP according to Reach to Recovery American founder Terese Lasser, is three-fold; “first, give weight to the side of the operation ... second, go around a little on the side and on the top when necessary, thus helping to take the place of the lost muscles; third, give back her figure. Unless it does all three, it is not fulfilling its purpose” (Gardner, 2000 quoting Lasser (1953), p. 576).

Prosthetic breasts -- as many other artificial body parts have over the years -- have served their users by replacing a missing or amputated part of the body, and indeed have proven to be practical. They have also provided psycho-social and emotional-body-image-identity support and benefits embraced by many post-mastectomy women. Nevertheless, the overarching question remains -- where does a woman’s agency to choose “to wear or not wear” lie -- as a clear choice in the triad of post-surgical, survivorship breast cancer cultural choices?

For some women, EBPs can be a vital part of the mastectomy healing process, as well as offering a benign alternative to reconstructive surgery (Gardner, 2002; Jetha et al., 2017; Canadian Cancer Society, 2019). However, as Sociologists, it is essential to delve into the reasons why women are motivated to wear EBPs in the first place. Jetha et al. ’s research asked a cohort of women this same question and among the results noted, said they used them because “they felt strange, incomplete, and embarrassed in front of other people, due to the asymmetrical shape of the chest after mastectomy.” Their respondents’ emotions harken back to the touchstone concept of stigma, with its contextual meaning that underscores social relationships in its application to the human experience of it -- “Importantly, stigma is relationship-and-context specific; it does not reside in the person but in a social context” (Major & O’Brien, 2005, p. 395). In other words, when alone, one may not be likely to feel it.

Although breast prostheses have taken on the aura of a ‘medical device’ -- perhaps since the early 1900’s as Gardner’s historical account notes, when some patent filings showed a shift from aesthetic value to a medical application in terms of the inventors’ articulation in writing, of the overall purpose and reasons for their use -- nevertheless, the author notes that in Gardner, 2002, p 102: “The prosthetic business is also a beauty business, however, and the breast form serves a cosmetic purpose. Therefore the evolution of this industry has benefited from the emphasis that American society places on female beauty, specifically on images of perfect breasts” (cited from Gardner, 2000, pp 586-587).

### **The wearing of breast prostheses: lived experiences.**

In 2015 Liang & Xu published a systematic review of the identification of various variables that could influence post-mastectomy women's use and degree of satisfaction with their EBPs. Interestingly, most articles relevant to the topic of EBP utilization were written by Australian scientists, with a post-surgical rate of use of up to 90% reported among western countries. After the final selection process, a total of 18 papers were reviewed; of these, six were Australian (some by the same author), three from China, two from Ireland, and one each representing Canada, USA, France, Germany, the Netherlands, Poland, and Brazil. Of these, six used interviewing as their method of data collection.

The results identified six main factors that influence EBP use worldwide: comfort, cost, appearance, mental status, reconstruction, and information. The comfort factor came out as one of the major ones that exerted a strong influence regarding utilization and satisfaction. Comfort was most influenced by the weight and material used in the construction of the EBP – the heavyweight of the device primarily caused shoulder pain, so users were more satisfied and inclined to wear a light-weight type versus a basic model. Manufacturers seem to prefer producing EBPs out of silicone – making them hot and sweaty in the summer and cold in winter. It was also noted that the adhesive variety tended to increase the risk of developing severe skin rashes beneath the stick-on adhesive strips.

Factors influencing women to choose EBPs instead of reconstruction included: lack of relevant information, lack of family support, fear of complications, and perception of being too old for surgery. When they focused on cost, the researchers found that most users chose cheaper models opposed to a comfortable one, or were unable to replace their EBP due to a lack of money – therefore making the cost-price-factor a significant one.

Psychological issues included a subset of psychologically distressing matters that included feelings of having an abnormal body image, (daily) reminders of their breast loss and inability to adapt to their breastless circumstances and their EBPs as well as feelings of fear and anxiety of 'awkward moments' (Liang & Xu, 2015, pp 218-224). Jetha et al details examples of these 'awkward moments' from their interviews with wearers of EBPs, who recounted highly embarrassing wardrobe mishaps in public social situations, where due to a bra riding up, both EBPs came out and reached her neck, in the other instance the EBP dislodged from her bra and

fell on the floor in front of everyone. In both cases, the women felt so humiliated; they felt compelled to leave and go home (Jetha et al., 2017).

In their conclusions Liang & Xu point to the fact that although their literature searches were performed as broadly as possible, they realize that the number of relevant articles that were ultimately identified was relatively small. As well as being a limitation in their study, this they interpreted as just another indication of the low level of concern the breast cancer research world has for the quality of life aspect of EBP wearers internationally. It appears that not much interest is being paid to whether EBPs are serving the needs of post-mastectomy women effectively or not.

### **Prosthetic Breasts: To Wear or Not to Wear?**

Klawiter discusses “the remarkable extent to which disease regimes and illness experiences can, under certain conditions, be transformed by social movements” (Klawiter, 2008, p. 230). The author segregates breast cancer into two distinct “regimes” of practices – the first as the “regime of medicalization” arising in the early decades of the 1900s, which transitioned into the second regime of “biomedicalization” during the 1970s and 80s. By the late 1990s breast cancer practices had changed into their second phase. Each regime had its own distinct characteristics. The first was distinguished by several, including: the sovereign power of physicians – particularly surgeons, isolation and disempowerment of patients, and the invisibility of women with breast cancer and mastectomies in the public domain. The second saw new practices enacted, such as breast cancer education, early detection, diagnosis, disclosure, treatment and rehabilitation (Ibid, pp xxvii, 230).

Referring to her interview with a woman who had had a mastectomy in the late 1970s, Klawiter critiques the Reach to Recovery program. One of its cornerstones is the breast prosthesis. Originating in New York in 1952 by founder and breast cancer survivor Terese Lasser, (who states she was motivated by total isolation and absolutely no support resources to turn to) it was formally brought into the American Cancer Society (ACS) in 1969 as part of their rehabilitation and support program, and is still in operation via the ACS in the USA to this day.

The program matches trained volunteer breast cancer survivors to women who had just had a mastectomy and are living with breast cancer. An essential part of their program is to give hope to other women that they too can survive breast cancer. However, the mandate their volunteers

are trained in included educating women on prostheses, how to return to normal as quickly as possible, and how to dress in order to "... minimize looking like you'd had a mastectomy..." (Klawiter, 2008, p. 234). These edicts have been criticized over the years by activists such as American Audre Lorde and Canadian Darlene Betteley.

Perhaps Reach to Recovery program goals for supporting a woman of the 1950s into the 1960s recovering from mastectomy surgery became outdated for a woman of the 1970s. Lorde's objection to their program focused on their encouragement of "the woman to concentrate on breast cancer as a cosmetic problem," 'one which can be solved by a prosthetic pretence'" (Lorde, 1980, p. 55 in Batt, 1994, p. 230).

In 1990, Darlene Betteley of Kitchener-Waterloo Ontario was expelled as a volunteer from the Reach to Recovery program, at that time -- a part of the Canadian Cancer Society (CCS), because she refused to wear bilateral breast prostheses when she met with women who had asked for their support services after being diagnosed with breast cancer. She had been told by the CCS, "We like our volunteers to look normal." Betteley stated to the CCS in a letter that "...I decided for my own personal comfort, not to wear a prosthesis ..." According to the CCS's mandate, this was not in any way an acceptable reason for Betteley's display of her visible, flat-chested breastlessness, and her volunteer status was revoked (Batt, 1994 pp 224-226). That is to say, the volunteer was required to literally embody the appearance of a two-breasted, "cancer-free," "attractive," "hetero-feminine" woman -- bearing the gift of a temporary cotton prosthesis to the bedside; all the while acting as a role model -- motivating the breast cancer surgical patient to "get well" (Klawiter, 2008, p. 119).

Is it possible and probable, for the next 'regime' to include normalizing and making it acceptable -- eliciting and motivating a process of de-stigmatizing women who have had breast cancer and found themselves uni-breasted or breastless following mastectomy? Is it plausible in the future, that if they choose not to wear prosthetic breasts to hide their breast cancer and subsequent mastectomy history, then the socio-biomedical-political gaze will respect that, just as society learned to respect and almost revere and admire the "Bald is beautiful" women undergoing chemotherapy? The "Bald is Beautiful" campaign became a campaign of desire directly from the pharmaceutical companies to the consumer.

Although this direct-to-consumer campaign was created by a chemotherapy-producing pharmaceutical company with a plentiful budget and launched in the media, with heavy usage of



television advertising, (Klawiter, 2008, p. 293) – following along the thread discussed by Klawiter – could the third wave of breast cancer culture-regime spawn such slogans as “Flat is Flattering – choose comfort over convention” or “My emotional labor stops here – if my flatness bothers you, look away now!” or “My human rights include what not to wear on my body”?

If not wearing a wig and ‘going bald’ out in public and on camera came to be considered empowering, could ‘going flat’ and ‘staying flat’ and living a ‘flat positive’ life in private and public come to be viewed the same way? The “Flat and Fabulous” grassroots on-line flat support movement started in the United States in 2013 by two post-mastectomy women, aims to do that. As Sharon Batt states, “A woman with cancer who confronts the world with her baldness or breastlessness has tremendous power to effect change” (Batt, 1994, p. 236).

### **Sociocultural responses to mastectomy: Hegemonic-dominant response**

All “intelligible discourse” has some ‘code’ operating at its core level (Hall, 1980, p. 132). Social codes can include all types of verbal language, bodily codes such as appearance, commodity codes of clothing and fashion, and several behavioral codes such as protocols, rituals, and role-playing (Chandler, 2017). Women’s choices are not merely the expression of their compliance with a hegemonic ideology; they reflect their embodied needs and agency in their context.

Abiding by what seems to some women to be irrational norms is also a threat to women having actual agency – there is the possibility of judgments on each side. These currently medically available, normative choices are not presented by this research project as inherently superior, better or to be viewed as any type of an ideal, but rather as options that may come from some women’s needs and their individual ways of coping with the changes that breast cancer surgery brings to their bodies and body image.

Dominant discourse contains the ideologies of the dominant social group, and therefore, it is implied from an assumptive position, that messages originating from within the dominant culture will have the “latent meaning of the text... encoded in the dominant code” (Ibid, 2017). The embracing and full acceptance of the dominant-culture along with its socially and medically preferred messages usually manifest in a woman reproducing the limited, medically-constructed choices conveyed; that is -- to have her breasts reconstructed or wear external prostheses. The woman who takes this stance aligns with the medical view that it is unnecessary and perhaps

even unacceptable to live with a breast-amputated body. Her identity is that of a breast amputee with a temporarily abnormal, deformed body. She feels that her body ought to be either repaired or hidden beneath artificial breasts if reconstructive surgery is not medically possible or available (Lorde, 1980; Kasper, 1995; Zimmerman, 2000; Price Herndl, 2002; Uroskie & Colen, 2004; Young, 2005; Cromptvoets, 2003, 2012; Schulzke, 2011; Wegenstein, 2016, 2017; Canadian Cancer Society, 2019; American Cancer Society, 2019).

Providing she has no medical-surgical or logistical barriers for undergoing reconstructive surgery, she can feel optimistic that although she has temporarily experienced breast loss, she will have the chance to regain her “lost femininity, sexuality and normalcy” through breast reconstruction (Cromptvoets, 2003, p. 137). The second of the two choices usually presented to her may also be “chosen” if she is not able to have the reconstructive surgery. She may then be shown that she can still feel hopeful of feeling feminine, having a sense of sexuality, appearing ‘normal’ and ‘womanly’ in her self-identity at home and in public, with the help of external breast prostheses. She is told that they will assist her in recreating, when clothed, a breasted appearance of “wholeness” from a breast-amputated flat chest (Lorde, 1980; Batt, 1994; Kasper, 1995; Gardner, 2000; Young, 2005; Schulzke, 2011; Cromptvoets, 2006, 2012; Canadian Cancer Society, 2019; American Cancer Society, 2019).

With this dominant response, the mastectomized woman shares and accepts in its entirety, the embedded message coded within the medical system. Some of the ways she could receive this dominant cultural discourse are verbally during her medical appointments with doctors and allied health professionals, via written information with images in medical pamphlets she may be given, and through various national and mainstream printed sources or online breast cancer websites -- that uphold the normative heterogenic “pink ribbon” breast cancer culture of the “she-ro” through written texts, images and videos (Lorde, 1980; Sulik, 2010; Klawiter, 2008; Cromptvoets, 2006; Jain, 2007, 2013) or disseminated second-hand via family, partners, friends and colleagues.

### **Dominant Body Norms**

Three cultural norms significantly govern women’s choices post-mastectomy: feminine appearance, body part replacement, and healthy body appearance. Several perspectives are taken up by women who undergo mastectomy regarding these dominant body norms. Their views are embedded within the media interview material I have identified in this study and will be analyzed

to these three norms. Some are accepting of these norms, some are ambivalent, and others are critical of them. This thesis focuses on women's innovative creation of more post-mastectomy options. Such innovation builds on, reworks, and in some instances, rejects existing norms.

## Introduction

I will now take these three dominant body norms: the Norm of Feminine Appearance, Norm of Body Part Replacement, and Norm of a Healthy Body Appearance and deal with each one by creating a separate analytical chapter. My focus will be on the 'flat narrative' – relating specifically to the 'go flat' movement and its discourses. The purpose of my other examples, which demonstrate the undergoing of reconstruction and the wearing of prostheses, is to provide a counterpoint to the flat discourses.

The current nascent 'flat movement' can be viewed as inspirational, but at the same time, it can also be interpreted as a threat to status quo breast cancer cultural norms, such as in the experience related by Price Herndl. Recounting her breast cancer experience and subsequent autologous unilateral reconstruction, the author uses the writing of her essay three months after her mastectomy, as a way to work through her conflicted feelings regarding her decision to *not* stay single-breasted following her surgery. Herndl alludes to feeling disappointed in her self because she was not able to resist having breast reconstruction. She states: "I warn you up front that it is about the conflict of finding myself at odds with a feminism that I greatly admire and about coming to terms with not living up to Audre Lorde" (Price Herndl, (2002), 2009, p. 477).

The perspectives of the women quoted in these chapters have all dealt with some type of a breast cancer diagnosis or a breast cancer genetic threat and have had some form of breast cancer surgery, either therapeutically as part of their medical treatment plan or prophylactically as a preventative measure decision based on genetic testing for BRCA-1/BRCA-2 or other identified breast cancer genetic risk factors or family history. These women's lived experiences of breast cancer, and the decision-making they have engaged in pre and post-operatively can be viewed as their efforts to create more and acceptable options for themselves, as they navigate ways in which to live with their new normal after having had their natural breast(s) amputated.

Presented here are the views of those for whom these existing norms work in part. What will also be considered are ways in which they do not work for some women – as a growing number of women appear to have a problem(s) with these norms and are expressing this in their post-mastectomy body practices. These corporeal practices exhibit, embody, symbolize, and manifest

in these women's profound ways of being selves. Different body practices have different meanings. These will be explored. With the telling of the going flat narrative, these norms are made manifest – made visible in various ways.

Their flat narratives are those of resistance – tales of rejecting and resisting reconstruction and the wearing of prostheses. In Arthur Frank's (1995) pivotal work *The Wounded Storyteller: Body, Illness and Ethics* he conveys his belief that the illness narrative has its own power, by engaging in the act itself -- "Telling stories is a form of resistance" (p. 170). Frank identified the growing disconnect between a North American medical-health care system that has seemingly stagnated in a modernist era, while most of the recipient-patients of that care have forged ahead into postmodernity. The postmodern illness narrative involves a patient's ownership of her voice. With the telling of her illness narrative, in this case, a woman with breast cancer, she comes forward "to speak rather than (be) spoken for and to represent (herself) rather than (be) represented" (p. 13). Resisting, rejecting and refusing to hide or camouflage their mastectomized chests nor to participate in the front stage dramaturgy of body normalcy -- pretending that a breast cancer diagnosis has never affected their bodies and lives. Committed to displaying and living their authentic selves. These problems regarding norms not working for some women are not universally a problem(s) – they are do not carry an intrinsic factor of being "bad" as norms. Norms are not inherently "bad" for some people and by extension, some of these women. Why do these norms work for some women and not for others? Social categorizations such as age, race, class, religion, education and gendered responses of cis-gender or LGBTQ community members are all factors that impact how each woman experiences these norms.

### **Norm of Body Part Replacement: A Brief History of Breast Reconstruction Surgery**

In Western medicine, the medical model of disease uses a set of assumptions that started with Descartes' 17th-century division of man into mind and body, now referred to as the classic Cartesian dualism. Imagining the machine metaphor for the human body, with its various mechanical workings powered by a main heart pump, Descartes viewed an ailing person to be similar to "an ill-made clock." Just over a century later, Italian anatomy professor Morgagni built upon Descartes' "body machine" concepts by identifying separate body parts as specific organs, which played a role as the "seats of disease" within the body. Soon medical science and the physician each had a part to play in this evolving medical model: "... it was the role of medical

science to research the corporeal body, while it was the role of the physician as a body-mechanic to restore the particular part of the body that was malfunctioning to normality” (Jones & Moon, 1987, p. 11).

Eventually out of the necessity of war field amputation surgery, this role would extend to the physician-body-mechanic replacing body parts, the majority of them eyes and limbs, with artificial ones - prostheses: “If the histories of medicine, the body, and rehabilitation constitute the intellectual skin of the prosthesis, then surely technology contributes to the scaffolding” (Ott, 2002, p. 16). As early as the 1950’s, the question of whether humans could be rebuilt was being asked in mainstream published articles, theorizing on the replacement of diseased organs or missing limbs with new ones. If “spare parts” could be created for cars, then in much the same way, already “... surgeons and researchers have gone to great lengths to make available to the ill and disabled, dozens of replacements for worn-out or destroyed parts of the body” (Serlin, 2004, p. 4). These pioneering stages paved the way for the advent of plastic surgery as the specialty we know today. The bio-mechanical task of “replacing” the amputated malignant breast organ -- to restore a woman’s body to a socio-culturally acceptable two-breasted normative feminine body image, fell to plastic surgeons.

Plastic surgeons Uroskie & Colen report that the development of breast reconstruction was premised on the goals of allowing “women to feel comfortable in clothing and eliminate the need for an often cumbersome external prosthesis” (2004, p. 67). Whether, historically speaking, women themselves were saying this to their doctors, and asking them for breast reconstruction for these two key reasons, would need to be researched as a separate project. Certainly today, many women do request breast reconstruction for precisely these reasons, which will be shown and explored in other parts of this thesis project.

A brief history of breast reconstruction reveals its start in Germany in 1895 when surgery professor Vincent Czerny undertook to “reconstruct” a breast out of the patient’s own body tissue (autologous). It was an existing fat tumor documented as “fist-sized” that had grown elsewhere on the patient’s body -- that he subsequently transplanted to the woman’s chest, to form a breast mound where the amputated breast had been (Ibid, p. 66). It is also relevant to note the authors’ use of specialized language in describing the process of breast reconstruction at times as “recreation,” “recreated breast” or “reconstruction,” and sometimes using “breasts” and at others “breast mounds,” “a mound,” or “mound restoration” (Ibid, pp 65, 66, 68). Some ambivalence as

to what is being created, recreated or restored appears to be showing through – is it a breast, or is it a facsimile in the shape of a breast mound?

Breast reconstruction's over-a-century evolution sees some retrograde milestones, such as Halsted's reprimanding of surgeons not to perform any reconstructive surgery on a cancerous breast or its environ, as he vehemently believed it presented a threat and a "violation of the local control of the disease" (Ibid, p. 65). Eventually, the use of Halsted's radical mastectomy gave way to new, more conservative surgical treatments of breast cancer. With this change, "Cronin and Gerow fathered the modern era of breast reconstruction with the introduction of the silicone gel breast implant in 1963" (Ibid, p. 66).

These authors also put forth -- as medical professionals engaged in their skilled craft as plastic surgeons, who routinely perform breast reconstructions as part of their professional practice -- that any breast cancer surgical patient can "... comfortably realize that she can exist with a recreated breast that looks and feels like very natural (sic)." They assert that obtaining a reconstructed breast has now become a "routine choice" for women who require surgery for breast cancer -- communicating their medically based ideology that "The idea that a woman must live without a breast is a notion of the past" (Uroskie & Colen, 2004, pp 65, 68-69). For many women who undergo mastectomy for breast cancer, this is welcome news.

## **Theoretical Framework**

### **New Words**

In terms of breast cancer culture, new words have emerged to describe newly emerging 'new normal' breast cancer bodies. Breast cancer bodies that, until recently, have very rarely been seen in the public domain – clothed or unclothed -- except for some of the now notable forerunners who include Deena Metzger (unibreasted – 1988 with a tree branch tattoo), Audre Lorde (unibreasted -- 1980), Jo Spence (unibreasted lumpectomy – 1982), Darlene Betteley (bilateral mastectomy; no reconstruction/prostheses – 1986), Joanne Motichka Matuschka (unibreasted – 1993) and Lynn Kohlman (bilateral mastectomy; failed reconstruction then no prostheses – 2005). Although words such as: 'going flat,' 'living flat,' 'staying flat,' 'flatties' and the 'flat movement' are seen as part of this same cultural phenomenon, they were not coined or employed during these women's historical trajectories and began to evolve relatively recently.

An important starting point in thematic analysis is to look at the appearance of new words within cultures and our societies. In the context of this thesis, these new words are paired with new looks and appearance, new representations of women and their bodies. In this case, words such as ‘going flat,’ ‘living flat,’ ‘staying flat,’ ‘flatties’ or the ‘flat movement’ -- “constitute new self-understandings and perceptual experiences. Likewise, bringing an expression into the public can change the mood, climate, and focus of a group. Once an aspect of our experience is articulated, given language and public expression, we have a different access to it” (Given, 2008, p. 462). This thesis project aims to access this new vocabulary on an intimate level, which was created out of women’s breast cancer and mastectomy/post-mastectomy experience.

For many people, the symbolic meaning of women having breasts and displaying visual representations of them in some form or manner on their chests overrides the facts regarding post-mastectomy survivorship life, and the myriad of risks and all types of labor and suffering involved for women to achieve a ‘breasted appearance.’ The research I am undertaking is guided by the following socio-cultural theoretical perspectives as analytical frameworks – providing philosophical positioning, which will be used to study and interpret this socio-cultural phenomenon.

## **Introduction to Theories**

The selection of theories I have chosen, primarily those of Goffman, Hochschild, and Swidler will be used to create and demonstrate the salient links between my thesis vis-à-vis the concepts of dominant body norms; working in tandem with the sociology of emotion, and culture in action, and their interrelationship with the overarching issue of female identity regarding a socio-culturally acceptable two-breasted normative feminine body image -- in the absence of a breast or breasts. These notions will all be woven together to show how the defining catalyst of mastectomy surgery due to a breast cancer diagnosis or genetic risk factor and the pre and post-surgical decisions these women have made regarding ‘going flat’ and ‘living flat’ have become a socio-cultural phenomenon that has appeared in western society relatively recently.

Also considered and employed as an analysis tool in my work is Mahalik et al. ’s 2005 psychological measuring (psychometric) tool to assess North American-American women’s conformity or nonconformity to various culturally dominant feminine gender role norms. Part of Mahalik et al.’s work on their “Conformity to Feminine Norms Inventory” is based on social

constructionism and the theory that “gender role norms” – such as the concept of femininity and feminine norms – “are typically maintained by the reinforcement or punishment of social responses” (Mahalik et al., 2005, p. 417).

### **Goffman, Social Stigma and dominant cultural body norms**

This thesis will utilize Goffman’s approach to social stigma to analyze the physical stigma of breastlessness as an “abomination of the body” and for women who have had breast cancer, their mastectomies can serve as a stigma symbol, with the prosthesis acting as engagement in the act of what Goffman refers to as “covering” – “...since what will conceal a stigma from unknowing persons may also ease matters for those in the know...” (Goffman, [1963] 1986, p. 102). Via the medical and fashion industries, mastectomized women are culturally encouraged to perform a discourse of concealment (Wilkinson, 2001, pp. 271-272).

Dominant cultural norms regarding breast cancer culture will be questioned -- are they employed to hide a perceived “body abomination” and in turn to prevent stigmatization from occurring? Moreover, also employed to analyze the medical choices mastectomized women face in terms of reproducing the limited medical choices presented to them -- such as either consenting to breast reconstruction or wearing breast prostheses in response to the dominant body norm messaging sent by members of the medical community and its agents. This dominant body norm messaging can even be adopted and taken up by partners, family, friends, and co-workers, such as when these women may be asked questions such as “Are you going to reconstruct or wear false breasts?”

An alternate position women could uphold is taking on the stance of adapting and compromising to these dominant body norms, in order to increase their flexibility to the post-mastectomy situation they find themselves in. This adaptation could include such actions as the wearing of prostheses at work or in public, but not at home or in any private setting, unless strangers or visitors are present – in order to appear socio-culturally acceptable as not to incur rejection on any level or make others uncomfortable. This adaptive behavior may even be motivated by fear of losing their jobs if they do not appear to have a body that complies with and conforms to dominant ‘feminine body norms’ while in the workplace.

The tertiary option is taking on and manifesting a counter-dominant body norm stance, with a complete rejection of and in opposition to the limited medical choices prescribed to them – and



yet ‘offered’ as ‘choices.’ These acts and behaviors of rejection of women who ‘go flat,’ ‘stay flat’ and ‘live flat’ are turning away from and contesting the viability of these prescribed dominant body norms: Norms of Body Part Replacement, Norms of a Feminine Appearance and Norms of a Healthy Body Appearance.

This third interpretive position encompasses the ‘going flat,’ ‘living flat’ and ‘staying flat’ phenomenon. Cromptvoets calls this the “third choice” in which a woman may elect to “do nothing” about having a mastectomized chest and being single-breasted or breastless. This “choice” may be driven by a woman’s sense of body ownership and agency from the beginning – and having a conviction that reconstruction is something not right for her, a surgical procedure she does not want to have performed.

However, when there is indecision, ambivalence, and many ‘grey areas’ to navigate, through a variety of circumstances – from failed reconstruction, to clinical non-viability, to issues of geographical access or financial need to return to work and family caretaking; somehow the envisioned optimism, the vision of restoring a sense of body image and a ‘complete’ and feminine self -- where one will return to a previously experienced state of ‘normalcy’ through reconstructive surgery, may all too suddenly fade from view -- and permanently cease to exist as an option. It is while reconciling this as a reality, that “women are forced to renegotiate their sense of self without breasts” (Cromptvoets, 2006, pp 147-148).

Cromptvoets maintained that this “third choice” of “doing nothing” – in today’s terminology - - “to go flat” -- a term which was not in use until relatively recently, but not used at the time of her research – for a woman to “reconceptualize her body as normal, feminine and complete without breasts” was “utterly absent from breast cancer discourse” (Ibid, p. 148). In her concluding chapter, she lays out a blueprint for what could be, in terms of breast cancer protocols, policies and procedures that would address an array of these salient variables missing from this domain (Ibid, pp 147-150). She argues that when a woman makes a decision ‘to do nothing’ it is not respected nor seen as one that is “informed and competently made, rather it (is seen) as a deferral of choice.” That is, of the standard two choices that are routinely presented by agents of the medical community – to have reconstruction or wear prostheses (Ibid, p. 147).

Cromptvoets continues her argument by addressing the code of silence surrounding the mastectomized body. She maintains a position whereby when the dominant culture engages in continuing to reproduce “... the mastectomized body ...as something ...abnormal, unfeminine,

desexualized,...incomplete by and for women with breast cancer, is to remain silent about other avenues with which women can begin to understand and accept the new materialities of their post-surgical body” (Ibid, p. 148). At the same time, Cromptvoets underscores her belief that there should not be an interdependent relationship between whether a woman accepts her ‘new normal’ body being contingent on any other person or persons’ conditional acceptance or conversely, rejection of ‘it’ – her own body (Ibid, p. 148).

Hochschild’s approach to emotion management and emotional labor will help to analyze how women who feel most comfortable without a breast prosthesis in place, may, in fact, be forcing themselves to place one (or two as the case may be) on their post-mastectomy chests, no matter how physically, psychologically or emotionally uncomfortable, or perhaps even painful this may be. Motivated by ‘thoughts of others’ and not wanting to make others in their company feel uncomfortable or awkward, they instead will take on the “emotional labor” (Hochschild, 1983, p. 7) and physical labor of the discomfort and awkwardness.

### **Swidler: Culture in Action**

Looking at definitions of culture –

Sociology understands culture as the languages, customs, beliefs, rules, arts, knowledge, and collective identities and memories developed by members of all social groups that make their social environments meaningful. (American Sociological Association, 2019)

Swidler’s classic 1986 article, “Culture in Action: Symbols and Strategies” presents an “alternative view of culture,” and set the stage for giving us the “tool kit” metaphor along with fresh academic views for cultural analysis – innovative analyses which can demonstrate how “Culture influences action...by shaping a repertoire or “tool kit” of habits, skills, and styles from which people construct “strategies of action” – meaning “persistent ways of ordering action through time” (Swidler, 1986, p. 273). These “strategies of action” can be used in attempts to figure out -- with the goal of trying to resolve via conscious, strategic acts and actions of cultural practice -- issues and challenges that originate and are embedded within the institutional, cultural structures we inhabit within a larger, overarching society.

Swidler’s tool kit metaphor approach is a concept that forms the beginnings of a workable and useful theory of culture that can be employed as tools in the processing of the loss of breasts and ways of coping with breast loss. These tools formed from habits, skills, and styles will come

together to form strategies that enable women to go about putting other tools in their breast cancer toolbox – thus creating new narratives. Dominant discourses influence our tools.

The tool kit a woman might choose according to her values, assumptions, and attitudes toward her breast cancer “depends on her system of beliefs and, to an even greater extent, on cultural authorization” (Zierkiewicz, 2012, p. 41). In his *Recovering Bodies*, Couser created this term “cultural authorization” to encompass the concept of social sanctioning – “the sense that their story is valid and valuable” (Couser, 1997, p. 12). Zierkiewicz’s understanding of cultural authorization is “general social acceptance of given views, behaviors and actions” (Zierkiewicz, 2012, p. 41).

According to Couser, when the expression of illness stories is in a “more public form” – this apparently can lead to the necessity of a “stronger social sanction” (Couser, 1997, p. 12). The concept, narratives, and behaviors of the very public and higher profile “going flat” and “living flat” movement could very well fit into Couser’s model. He believes that until sometime in the 1990s, the cultural authorization to validate and recognize the value of illness narratives had been “lacking” (Ibid, p. 12). He also asserts these narratives as such -- in this thesis’ case -- flat breast cancer narratives, have a “common purpose” – which is to “invalidate dominant cultural narratives of invalidism” (Ibid, p. 12).

A dominant cultural narrative of invalidism that could be interpreted from Zierkiewicz’s work regarding breast cancer expresses the notion of how women are given the message not to be fearful of breast cancer. The implied rationale according to the author is that the worst-case scenario conveyed would be that your diagnosis will involve a mastectomy, but not to worry, because with available breast reconstruction “you will have everlasting firm and perfectly round breasts, which will improve significantly their quality of life” (Zierkiewicz, 2012, p. 39). It can be asserted that currently, this message has almost taken on a trope-like status within breast cancer culture.

The go flat movement engages in resistance to this type of message in a variety of ways – providing new tools based on new ideas versus traditional, familiar, practical, time-honored habits -- in the cultural repertoire will enable everyone, all women, to use these tools if they wish. These are the perspectives of women who are engaging with dominant cultural norms and in the process, are creating more options for themselves, and by extension, other women who enter the breast cancer continuum.

Swidler developed two models of “cultural influence” – one for what she terms “settled” cultural periods and another for “unsettled” cultural periods. Summing up “settled culture” in a single word – it is driven by *habit*. She defines a “settled culture” as one that has its “traditions and common sense,” which is characterized by an encapsulation of cultural views (Swidler, 1986, p. 282). In the short-term, settled culture offers “weak control over action” (Ibid, p. 282). Swidler describes its long-term effects as capable of providing “resources for constructing strategies of action” (Ibid, p. 282). She explains her belief that during periods of settled culture, humans appear to live “settled lives” within it. Nobody seems to need to rock the boat. Within an era of cultural stability, a person “refines and reinforces skills, habits, modes of experience” and depends on their “strategies of action” that are considered the proven and dependable ones to employ in his or her everyday life. Astutely, she observes that “...gaps between explicit norms, world views, and rules of conduct individuals espouse and the ways they habitually act create little difficulty within settled strategies of action. People naturally “know” how to act.” (Ibid, pp 280, 282).

Conversely, describing an “unsettled culture” with one word would be to say that *ideologies* – new ideas drive it. New ideas lead to innovation and inventions – new ways of dealing with sometimes old problems. Swidler refers to these as “explicit, articulated, highly organized meaning systems” that “establish new styles or strategies of action” (Ibid, p. 278). Here she describes a “continuum from ideology to tradition to common sense” (Ibid, p. 279). During times that are considered to be culturally “unsettled,” the “unsettled culture” is characterized by its competing “with other cultural views,” there is in the short-term, “strong control over action” as it “teaches new modes of action” (Ibid, p. 282).

Societies will experience, in the form of a transitional movement -- that which sees a gradual ebbing of using these former traditional habits to a flow of employing new ideas. It is these ideas that will determine the actions undertaken. Ideas generate forward movement along the human life continuum, with habits based on tradition as sometimes contributing to stagnation and dogma. However, there may be limitations to the general long-term adoption of new ideas, as Swidler expressed, a person living in a time of unsettled culture “creates new strategies for action, but long-term influence depends on structural opportunities for survival of competing ideologies” (Ibid, pp 273, 278 to 282).

Linking these with contemporary views of culture, celebrated musician-cellist Yo-Yo Ma believes in a version of this same overarching Swidler argument, "...culture is essential to our survival. It is how we invent, how we bring the new and the old together, how we can all imagine a better future" (PBS.org, PBS News Hour, April 15, 2019). Ma stretches these concepts out and extends them to include the idea that no matter through which medium of culture we tell our narratives, they will ultimately always be human tales – stories that have the ability to unify us "as a species." It is via this unification, that culture shows itself to be a powerful tool for humanity – capable, according to Ma, of turning "the other into us" – accomplishing this through "trust, imagination and empathy" (Ibid, April 15, 2019), thus giving hope to the transcendence of difference. These concepts can all be applied to the going flat movement and some flat positive advocates' belief in a "better future" for women who undergo mastectomy for breast cancer.

During the years this thesis was researched, from 2016 to 2019 present day, could be considered as broadly belonging to an unsettled cultural period, a period of "...social transformation" which seems to "provide simultaneously the best and worst evidence for culture's influence on social action." A time in which "Established cultural ends are jettisoned with apparent ease, and yet explicitly articulated cultural models, such as ideologies, play a powerful role in organizing social life" (Swidler, 1986, p. 278). An epoch in which people in the western world increasingly undertake the questioning and challenging of institutional authority and its agents.

In the context of this thesis research project, a growing number of women with breast cancer who have had mastectomy surgery appear to be challenging the medical authority of their physicians by rejecting the breast reconstruction or external prosthetic breasts that are offered to them pre or post-mastectomy. With their new ideas – their strategic acts and actions of cultural practice, regarding how they wish to cope with breast cancer mastectomy, can be viewed as a strategy to deal with the "problem" of the breastlessness that results from breast cancer surgery. This attempt at resolution of this conflict and issue of this unacceptable and undesirable "abomination of the body" with the subsequent displaying of a female body without breasts in public is an issue and a challenge that originates and is embedded within the cultural, institutional structure of medicine we inhabit within a larger, overarching society -- and the medical norm mantra: "That a missing body part must be replaced."

The women who are turning to living a ‘flat positive life’ could be seen to have lived through the continuum cited by Swidler; moving from “ideology to tradition to common sense” (Ibid, p. 279). That is, it is conceivable to say in this thesis’ context -- the historical ideology of hiding the breast cancer mastectomized body (as a shameful, terrifying secret -- and stigmatized “body abomination”) -- underneath prostheses, became the traditional way of dealing with and handling breast cancer. This habit or tradition eventually led the way to camouflaging by employing breast reconstruction technology -- as following the medical ideology of body part replacement at all cost. Historically, medically and sociologically, these two elements melded into the dominant female body norm and dominant breast cancer cultural norm of ‘how to do breast cancer.’

It can be suggested that now, in this “culturally unsettled” epoch, women who have experienced breast cancer and mastectomy are utilizing a new cultural tool from their tool box; one that involves a strong element of common sense and cultural agency, with the capacity to act – that is, to ‘go flat’ and reject breast reconstruction and the wearing of prosthetic breasts – and to live a totally ‘flat life’ – not engaging in hiding or camouflaging their breastless chests.

Swidler exports these (1986) concepts and expands upon them in her 2001 work dealing with “cultured capacities and strategies of action” (Swidler, 2001). She introduces her inquiry and analyses of how humans “...make use of culture...” and “...what they use it for” (Ibid, p. 71). Coining the term “cultured capacities” a person uses culture in the formulation of the self – in constructing, maintaining and refashioning it, which are the “cultured capacities” that make up a social “actors’ basic repertoires for action” (Ibid, p. 71).

In the context of breast cancer and mastectomy -- can cultured capacities be used as a problem-solving strategy by mastectomized women to deal with their chests that become void of breast tissue due to breast cancer? This will be explored and employed as a tool of thematic analysis in this section as well. It is crucial to keep in mind Swidler’s belief that “...individuals maintain cultural capacities for varied strategies of action which they mobilize differently in different situations;” suggesting that “...the cultural influences individuals and groups carry into new situations are those that form their capacities for action...” (Ibid, pp 83-84).

Women’s responses to having breast cancer and subsequent mastectomy are not homogenous, one dimensional nor stereotypical as are often held up by dominant medical norms messaging (Kasper, 1995; Crompvoets, 2003, 2006, 2012; Wegenstein (Slezak in *The Good Breast*), 2016) and are as diverse as the women who undergo this surgery (Kaiser, 2008).

The dominant and most ubiquitous image of a woman who continues to live following diagnosis and treatment as a breast cancer ‘survivor’ or ‘She-ro’ is “most often represented as triumphant, happy, healthy, and feminine” (Kaiser, 2008, p. 80) citing Batt, 1994 and King, 2006); (Sulik, 2011). Although North American breast cancer fundraiser events built around a communal walk or run such as the Susan G. Komen Race for the Cure, and according to its website is the “World’s largest and most successful education and fundraising event for breast cancer – Worldwide since 1983.” (The Susan G. Komen Breast Cancer Foundation, Inc. (US), 2019) – However, “mastectomy scars and disfigured bodies are hidden at the Race. Prostheses makers and cosmetic companies at the Race and at other breast cancer walks encourage women to project an image of wholeness and femininity” (Kaiser, 2008 p. 80, citing King, 2006).

Citing Swidler’s cultural sociology (1986, 2001) and her “tool kit” metaphor, Kaiser (2008) explains, from the genesis of Swidler’s 2001 *Talk of Love*, that somehow people decided to “use some cultural materials while rejecting others, especially as they attempt to “retool” their lives following a major life event or transition” (Kaiser, 2008, p. 82). In popular culture, retooling can be seen as a type of “re-inventing” oneself, especially after some crisis – particularly when it comes to issues of an altered physical body, resulting in a changed body image. In Kaiser’s research work on “Survivor Identity for Women with Breast Cancer” she utilized Swidler’s “tool” theory to demonstrate how the breast cancer survivor “identity” could be seen as a type of “tool” used by women diagnosed with breast cancer, in order to “become a certain kind of person... Given the disfigurement, disruptions, and ontological insecurity brought by cancer (Mathieson & Stam, 1995; Nelson, 1996), it makes sense that women would use survivorship to organize the self and life.” (Ibid, p. 82).

### **Application of Goffman, Hochschild and Swidler’s theories to Mastectomized Women and The Cultural Phenomenon of ‘Living Flat’**

Plastic surgeons Platt et al. have written in their research work on mastectomy and breast reconstruction, citing Morrow et al. (2001), that “...the selection of mastectomy with reconstruction may be preferred by those who want to avoid radiation and the stigmata associated with having a mastectomy defect” (Platt et al., 2011, p. 2113). Goffman follows the trail of the meaning of stigma from its social use in ancient Greek society, and its original meaning of literally branding a person due to his or her “unusual or bad” moral status, to today’s usage of the term widely applied to an individual’s “disgrace” of varying types; being a ‘marked’ person with

deeply discrediting attributes that reduce the person “in our minds from a whole and usual person to a tainted, discounted one” (Goffman, [1963] 1986, pp 1-3).

According to Major & O’Brien “Most stigma scholars regard stigma as a social construction – a label attached by society – and point to variability across time and cultures in what attributes, behaviors or groups are stigmatized. Importantly, stigma is relationship-and-context specific; it does not reside in the person but in a social context” (Major & O’Brien, 2005).

De Courville Nicol describes fear and desire as “distinct yet interdependent motivational forces whose purpose is pain avoidance and pleasure seeking” (2011, p. 24). She suggests that the feeling of stigmatization is “the fear triggered by the perception that one lacks the ability to prevent being marginalized by others as a result of being visibly disturbing, whose pair is attractiveness” (Ibid, pp 38, 40).

Within the situational conditions of stigma and mastectomy, emotional conflict and anxiety typically manifest within mastectomized women. These painful feelings arise due to the socially constructed nature of the emotions involved with choosing either to hide or to allow her absent breast(s) to be ‘obvious.’ These emotional experiences happen within the context of our present North American western cultural climate of the beauty myth, and intense androcentric cultural gaze toward women’s breasts.

If a woman chooses not to conceal her breast amputation(s), a painful awareness seeps in, that now she will not meet the prescribed standard and dominant hegemonic assumption that ‘a woman is not really a woman, unless she has two breasts.’ She becomes fearful, as her insight into risking marginalization for being ‘visibly disturbing’ and ‘unattractive’ grows. For a woman to avoid any further pain of being stigmatized by not wearing a false breast externally or having one internally as an implant post-mastectomy; seeking the pleasurable feelings of being accepted by having a “normalized female shape” that breast prostheses could show to onlookers, is quite a seductive notion (Sulik, 2011, pp 38, 141, 332; Lorde, 1980; Crompton, 2006, 2012; Young, 2005; Batt, 1994; Yalom, 1997; Wegenstein, 2016; Price Herndl, [2002] 2009; Gardner, 2000, 2002).

Moreover, it is essential to acknowledge the historical roots of such notions as concealment and camouflage of the effects of mastectomy and the subsequent role they played in the medical and socio-cultural construction of ‘doing’ breast cancer and mastectomy. These ways and modes of doing would eventually, utilizing Swidler’s terms, follow a “continuum from ideology to



tradition to common sense.” Swidler refers to Geertz’s (1975) definition of common sense as referring to “the set of assumptions so unselfconscious as to seem a natural, transparent, undeniable part of the structure of the world (Swidler, 1986, p. 279).

When we first encounter a person unknown to us (a ‘stranger’), “first appearances are likely to enable us to anticipate their category and attributes, their “social identity.” How is a woman who is uni-breasted or completely breastless, to be ‘categorized’ by others during this initial meeting? Will she be addressed as ‘Sir’ or ‘Madam’? We transform these anticipations of others’ social identity into “normative expectations,” eventually developing them into “righteously presented demands.” In other words, we create a “virtual social identity” for the person in our minds, when, in fact, the person possesses an “actual social identity” rooted in his or her reality. When a discrepancy between virtual and actual social identity occurs, the person can be “reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, ((1963) 1986, pp 2-3).

In his work, Goffman defines the term “stigma” as referring “...to an attribute that is deeply discrediting...” and identifies three types of stigma: physical stigma (abominations of the body – various physical deformities), character traits (such as blemishes of individual character – weak-willed, dishonest, mentally disordered, suicidal, alcoholism) and stigma of group identity (tribal stigma of race, nation and religion). The common denominator in all three varieties is the sharing of:

the same sociological features: an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated. We, and those who do not depart negatively from the particular expectations at issue I shall call the *normals*. (Goffman, (1963) 1986, pp 1-5).

That is to say, that the stigmatized person’s central position in life is one of non-acceptance by the *normals*. Those *normals* who interact with him or her do not “accord him (...) respect and regard.” (Ibid, p. 8).

### **Abominations of the Body: Gimlin**

Gimlin concludes in her cultural work on the body that “The body might be a location of domination, but it is also a tool for resistance and agency in the construction and reconstruction

of contemporary selfhood” (2002, p.149). Women who have experienced mastectomy and are now living flat, appear to have done just that -- building on Gimlin’s concepts -- they appear to have used their single-breasted or non-breasted bodies to resist breast reconstruction and prostheses and reconstruct their new normal bodies and new versions of their feminine selves as women who just happen to be flat-chested. (Gimlin, 2015).

Gimlin’s interpretation of Goffman’s stigma work sees the category of abominations of the body as involving any “physical characteristics that compromise bodily appearance or functioning” – and can be viewed as “a form of deviance” regardless of how a person came by them – perhaps they were “acquired” by voluntary means or “involuntarily,” and totally out of their control -- such as at birth, by accident or disease – as in the case of breast cancer (Gimlin, 2015).

Abominations of the body are considered to be a form of deviance, and any form of deviance, especially a physical one of bodily appearance is not considered healthy, nor gives a healthy-looking appearance to the onlooker. Therefore, as a woman with breast cancer, who has undergone mastectomy surgery, she will carry the symbolism of the sick role, that of a woman who has had her breast cancer manifested visually in breast loss – a woman who has become ‘sick’ with breast cancer -- one who may not be able to fulfill her social role obligations as wife, mother, daughter, worker – a person in this sick role was also seen by Parsons ([1951] 1978) as displaying a form of deviance. According to Goffman and Parsons’ theories, women who go flat and live flat, risk being identified as ‘deviant’ and ultimately stigmatized by displaying a flat chest in public.

Physical characteristics that are deemed socio-culturally unwanted and unacceptable serve to isolate and ostracize those who possess them, thus preventing them from enjoying “full social acceptance.” From this point onward, once an undesirable physical attribute has been publicly displayed, then:

Everything about the stigmatized person is interpreted in light of the negative trait, so that interaction with the non-stigmatized is often awkward and uncertain. Tension is manifest in people’s tendency to avoid eye contact, make guarded references to the stigma, or avoid everyday words that suddenly become taboo; it leads both parties to consider avoiding or withdrawing from encounters (Gimlin, 2015).

Gimlin’s analysis also speaks to Serlin’s (2004) work relating to World War I and II and the concept of North American nation-building – where only healthy bodies were allowed to be

shown, in order to put forth as a metaphor, an image of a healthy, strong, developing American nationhood.

Stigmatized people may engage in various responses to cope or deal with their stigmatization, such as turning toward other stigmatized people for support. These often include starting or joining self-help groups or national societies and associations in order to feel a sense of belonging. Perhaps they may organize their own educational sessions and conferences or produce writings to increase self-esteem (Goffman, (1963) 1986, pp 9-22).

Further on in this work, I will discuss these coping responses in relation to women who have gone flat and are living flat. Several have created support and advocacy groups – one of the earliest being *Flat and Fabulous*, followed by other groups and ‘flat tribes’ such as *Flatties Unite*, *Flat in Canada: Support and Advocacy*, *Breastless and Beautiful*, *Tout aussi femme* Community Facebook page, *Fantastic Flat Fashions* and many others.

I will follow this thread in my thesis, touching upon and examining themes related to the fact that a woman who has one breast or no breasts and becomes known as either “uni-breasted” or “breast-less” is not considered to have a “normal” body. Society’s gaze (which is predominantly known for being a ‘male-oriented gaze’), expects her to have two matching breasts throughout her lifespan, from the time of puberty onwards into her elder years -- until the time of her death. Her stigmatization has the potential to become two-fold – one for having “diseased breasts from cancer” and the other for failing to be a “normal” two-breasted, symmetrical woman.

Goffman introduces the concept of “stigma symbols” to us – explaining that they are a particular type of symbol; symbols, in general, are widely used by humans in our societal matrix as part of a social information control system. They help us to make sense of and glean an understanding of others (most commonly in the first quick moments of an encounter). He gives the example of a wedding ring; when one wears it, it sends an information signal to others that the wearer is married. Sociologically, stigma symbols function much in the same way; they pass on information about a person’s stigma, for example, a wheelchair, white cane, hearing aid or skin color; even being considered by Goffman as the opposite to a status or prestige symbol (Goffman, (1963) 1986, p. 43).

Drawing a parallel with women who have had breast cancer, their mastectomies can serve as a stigma symbol, with the prosthesis acting as engagement in the act of what Goffman refers to as “covering” – “...since what will conceal a stigma from unknowing persons may also ease matters

for those in the know. It is thus that a girl who gets around best on her wooden peg employs crutches or an artful but patently artificial limb when in company” (Ibid, p. 102).

### **Hochschild: Emotional Labor**

Further to Goffman’s concept, a woman who feels most comfortable without a breast prosthesis in place, may in fact be forcing herself to place one (or two as the case may be) on her post-mastectomy chest, no matter how physically uncomfortable or even painful this may be -- motivated by ‘thoughts of others’ – not wanting to make others in her company feel uncomfortable or awkward, she instead will take on the emotional labor (Hochschild, 1983, p. 7) and physical labor of the discomfort and awkwardness.

Hochschild’s definition of emotional labor encompasses the notions regarding the management of feelings to create “publicly observable” bodily and facial displays compliant with social requirements; it also has an exchange value, when it is “sold for a wage”: “This labor requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others...” The author also uses “the synonymous terms emotion work or emotion management to refer to these same acts done in a private context where they have use value” (Ibid, p.7).

The application of Hochschild’s emotion management concept is galvanized in Pirok’s statement: “Ultimately, breast cancer survivors are tasked with easing cultural anxieties through their bodies and narratives” (Pirok, 2016, PhD Sociology Dissertation, University of Missouri). It is she who will perform her ‘social duty’ and emotion work in her role as a woman who is merely acting out the “... ‘restitution narrative’ (that) powerfully structures expectations of how a woman diagnosed with breast cancer will behave...” (Broom and Frank cited in Wilkinson, 2001, p. 270). These women will engage in the ‘performances’ discussed by Goffman, in which the post-mastectomy woman must believe in the part she is playing (Goffman, 1973, p. 17) – that she is in essence ‘fixed up and healthy again, ready to take on her womanly duties’ – as if nothing had happened to her. In this instance, she, in effect, sacrifices her own needs and level of comfort for that of others.

### **Sulik: Breast Cancer and Hochschild's Feeling Rules**

In 2011, Sulik's decade-long research on breast cancer culminated in the publishing of *Pink Ribbon Blues*. The author invokes Hochschild's classic "Feeling Rules" – all the socially sanctioned, expected, and obligatory feelings we are supposed to or not supposed to have in certain socio-cultural situations and discusses them in direct relation to breast cancer survivorship. In Sulik's interpretation of Hochschild – "Feeling rules provide a benchmark for gauging how to feel about social roles, relationships, bodies, and illnesses" (Sulik, 2011, p. 228).

She introduces three feeling rules she maintains "often occur simultaneously," and "encourage specific behaviors, coping mechanisms, and cultural repertoires" -- in her analysis of the "impact of social context on women's experiences of breast cancer and sense of self" (Ibid, p. 230). "Feeling Rule 1: Optimism - Survivorship requires a strong sense of optimism in terms of hope, faith, and transcendence. Feeling Rule 2: Selfishness - Survivorship necessitates selfishness, which is constructed in masculine terms as a rational coping strategy or as a confession of gender violations related to women's nurturance and selflessness. Feeling Rule 3: Guilt – Guilt results from the stigma associated with failing to present oneself adequately as a she-roic survivor, losing bodily integrity, or disrupting gender roles" (Sulik, 2011, p. 230).

If a look of the norm of healthy appearance is to be achieved, a breast cancer survivor is expected not to lose her bodily integrity, nor to think of what is best for herself and her body in ways that could be interpreted as being selfish. These could apply to women making the decision not to reconstruct and to go flat and to live flat – presenting her self in public without external artificial breasts. Displaying this type of body image could be interpreted as not having a healthy appearance.

Symbolic vestiges of the disease of breast cancer that invaded her body in the form of her visibly amputated breasts, could inspire a backlash of feelings of fear of this disease and illness in others, especially women – who may fear that they too are at risk of being diagnosed with breast cancer; perhaps suffering the consequences that such a diagnosis may bring – mastectomy surgery and the ultimate loss of a breast(s) -- as well as feelings of discomfort when people who view her chest are reminded of the harsh realities of breast malignancy. People may be fearful of having a daughter, mother, wife, partner or sister diagnosed and, during treatment, have their breasts amputated or even succumb to the disease. This fear, in turn, could spark feelings of anger and resentment in others who may feel that the living flat woman is not adhering to her

responsibility to cover up her mastectomized chest. She is failing to undertake the emotional labor necessary by putting others' feelings first -- in order to make others feel comfortable, not anxious -- and help them feel secure that she is healthy, and does not present a threat to society as a risky, unhealthy, abnormal, deviant, with the body of a sick person, and does not remind them of their own risk of cancer, breast cancer, or mortality.

The woman with breast cancer who undergoes mastectomy becomes vulnerable to a 'twofold' campaign of fear. She is positioned to fear not only the potential of her death from the disease but also the social disapproval resulting from structural and normative issues put forth by the messages 'imprinted' by the medical "institutional power" structures (During, 1993 p. 90). For example, medical professionals' opposition to non-reconstruction could potentially be manifested and achieved through a "fear campaign" and "emotion management" (De Courville Nicol, 2011, pp 180-81), whereby patients are discouraged from considering alternatives to breast reconstruction – after hearing fear-inducing messages from their medical team.

### **Fear Campaigns**

According to De Courville Nicol, a "fear campaign" is a type of "emotional campaign" – which "seeks to achieve certain ends" (De Courville Nicol, 2011, p. 180). For example, some medical professionals reportedly engage in a fear campaign in the promotion of their opposition to non-reconstruction ('going flat'), thereby producing fear in their patients in ways that curtail any consideration of alternatives to prosthetic breasts and breast reconstruction implants. In other words, the desire of a patient to 'go flat' is a contrary wish, one which is viewed as a shameful desire by medical authority. However, simultaneously, a desire campaign is launched by the medical authority. One in which the desire for breast reconstruction is a positive wish; enacting this surgery upon one's body will induce and produce prideful feelings within the mastectomy patient -- such as a feeling of pride in the restoration of a feminine body image.

As in the case of Joanna's media interview data which is part of this thesis (Zabjek, 2019) – when she was repeatedly told by her medical teams "how hard it would be" to not have breasts and that waking up from anesthetic without them would cause her to have "a psychological breakdown" (Ibid, 2019). This type of fear campaign sought to "repress or correct" Joanna's desire to have no breast reconstruction – "as a form of incapacity" (De Courville Nicol, 2011, p. 180) – potentially eliciting a fear and shame emotional reaction within the patient Joanna.

As in Joanna's situation, not having reconstruction, not wearing prostheses and 'living flat' is not only not introduced by doctors as standard practice, they omit to present it as an option entirely. As medical professionals, it appears that the majority is unable to recognize or accept 'going flat' as an option to be considered as part of professionalized breast cancer care. This attitude could be explained by noting that the Western physician has been trained, operates inside, and has taken part in creating the dominant breast cancer culture; noting as well -- also within the dominant body norms paradigm of body part replacement, healthy body appearance and feminine appearance. Physician training also speaks to the often one-dimensional notion of breast loss being based on "hyper-feminine norms" (Crompvoets, 2006, p. 146). Furthermore, acknowledgment of these conditions could help to explain why some doctors produce fear in their patients in ways that curtail any consideration of alternatives to prostheses and breast implants.

### **Emotion Management**

Embracing both De Courville Nicol and Hochschild's insights on Emotion Management (EM) – EM will be explored in this work through the concepts of shame and pride and emotional labor. Shame is addressed when oppositionally-stanced mastectomized women violate the norm in refusing to have reconstruction or wear breast prostheses, turning the trope of concealment and shame of having amputated breast(s) into pride. The feelings of shame, fear, and personal insecurity experienced in failing to meet the normative, feminine, androcentric beauty standard of a 'normal' woman become salient. In the majority of women, self-esteem is obtained by being successful in meeting a normative standard prescribed and encoded by the dominant hegemony and disseminated via various societal and institutional channels.

Pride can be interpreted as either feeling prideful regarding complying with the norm, or feeling pride at 'being flat, beautiful, and breastless.' This aspect of 'mastectomy pride' can be directly related and compared to the 'Bald is Beautiful' direct-to-consumer campaign launched by U.S. pharmaceutical companies engaged in the manufacture of cytotoxic chemotherapy drugs routinely used in the treatment of breast cancer, causing temporary hair loss (Klawiter, 2008 p. 293). It is a matter of framing the baldness or breast loss as a symbol of pride and beauty and resisting the emotion of fear and shame. It could also be interpreted that pharmaceutical companies needed women with breast cancer to not be fearful of receiving chemotherapy and

becoming bald; their marketing plans and profit margins depended on it. The campaign of desire aims at transforming a new or controversial socio-cultural practice such as ‘female public baldness’ as desirable.

Conversely, the fear campaign’s goal is to frame or transform a new innovation or controversial socio-cultural practice such as ‘going flat’ and ‘living flat’ as threatening. Controversial stances often produce conflict – the two campaigns drawing battle lines, engaged in an ideological conflict, with one seeking to undermine and conquer their opponent’s cultural beliefs and values. Women who eschewed the wearing of prosthetic breasts stand to gain self-proclaimed freedom from shame and fear, as they transition into a position of pride for being breastless and their ‘new’ authentic selves (Lorde, 1980).

### **Methodological Framework**

Known as and named within the current popular culture – this emerging ‘going flat–living flat’ phenomenon will be studied at the microsociology level. One locus of study will be on the individual, her media interviews and qualitative thematic analysis of media interview content of a currently relatively small, but growing socio-cultural pattern of breast cancer behavior initiated by post-mastectomy women, based on their lived experiences. Thematic analysis has been employed as the qualitative data analysis method, which will identify, assist to analyze and report on repeated, patterned, themed meanings across my data. This tool of analysis has been chosen because it is “a flexible approach that can be used across a range of epistemologies and research questions” and “allows for social as well as psychological interpretation of data” (Braun & Clarke, 2006, pp 79, 86, 97). I personally transcribed verbatim all verbal data into written form when an accompanying text version was not available. Several transcripts are typed texts, others hand-written. The verbal media interviews appeared in videos on websites or posted on YouTube, television news programs, and documentary film. Braun & Clarke, 2006 point out that a number of researchers see the transcription phase as “a key phase of data analysis” (Bird, 2005: 227) and is inherently “an *interpretive act*, where meanings are created, rather than simply a mechanical act of putting spoken sounds on paper (Lapadat and Lindsay, 1999)” pp 87-88.

These data will be examined for meaningful themes and symbolic content, with the aim of explaining, understanding, and interpreting their ‘going flat’ and ‘living flat’ behavior. Their patterns of behavior, actions, interactions, perceptions, and emotions will be studied under the



microsociology umbrella. Although the microsociology approach will be employed, my thesis topic necessitates the utilization of a macrosociology approach as well, to investigate and analyze the overarching culture, norms, and values occurring within the social dynamics matrix of this topic, which are all highly interdependent. These sociological concepts will be explored and examined as they relate to three selected dominant body norms of the breast cancer culture, which will be introduced further on in this work.

In this research project, I have endeavored to explore this phenomenon via gathering, examining and analyzing media interview results in the form of published or quoted statements made by women who have ‘gone flat’ and are now ‘living flat.’ In spring 2017, when I was planning this qualitative research, the prospect of locating and recruiting a diverse cohort of Canadian interview respondents from this specific ‘living flat’ group appeared dauntingly challenging at best. At that time, I had never encountered, seen in any form, nor met a ‘living flat’ woman in Montreal. I was also not aware of any Canadian flat advocacy groups in existence at that time.

Over the past few years, many breast cancer forums and support and advocacy groups have moved from public access sites to social media closed group platforms such as Facebook – making them inaccessible to researchers. Many of these digital locales state that they want to create a ‘safe place’ for their members; one where they can post photos of their flat chests – clothed or unclothed, receive encouragement, support, feedback and express themselves in authentic ways, without fear of criticism, reprisal or consequences. I am a member of one such closed member breast cancer and mastectomy support group, which I will anonymize as ‘XYZ Support and Advocacy.’ As a former breast cancer patient and a uni-breasted woman who always wears a prosthetic breast when in public, I joined for my support needs.

Besides offering support to women who have had mastectomies and have not reconstructed, it also advocates for living a public, ‘flat positive’ life, if any member wishes to receive support for doing so, but is not in any way opposed to women wearing external prostheses if they choose to. However, if a member decides to undergo breast reconstruction, they must leave the group and seek support from a group involved in the specifics of reconstruction support. Although many voices and narratives sourced on the Internet and in popular media have surfaced since my initial awakening to the ‘flat’ phenomenon in October 2016, my first encounter with a Canadian article dealing with Canadian women who were ‘living flat’ came in January of 2019.

Together with my advisor and members of my committee, while speaking to these practical, ethical, and time constraint issues, I decided not to seek participants for in-person or Face Time online interviews. In the absence of one-on-one participants to ask these study questions to as a preliminary research phase has dictated an inevitable necessity to engage in a type of ‘reverse engineering’ -- thus following and matching the published media interview answers existing in the public domain, to some of the proposed questions I am asking.

My secondary sources have been gathered over a period of more than two and half years, from a variety of published media that are publicly available such as material from online newspapers, magazines, and online media interviews, books, YouTube and Internet web sites, documentaries, television media interviews, as well as some academic sources from scholarly books and journal articles.

The ultimate goal of asking these virtual questions to my virtual research participants, in the form of their existing published media interview and quoted data – is to delve into and undertake thematic analysis of their potential answers embedded within their media interview responses – and in addition, by introducing these socio-cultural theories -- will be to enlist their help, in order to gain some insights into these women’s motivations for resisting breast reconstruction and prostheses after mastectomy.

This thesis will utilize Erving Goffman’s approach to social stigma to analyze the physical stigma of breastlessness as an “abomination of the body” and for women who have had breast cancer or genetic risk of it, their mastectomies can serve as a stigma symbol, with the prosthesis acting as engagement in the act of what Goffman refers to as “covering” – “...since what will conceal a stigma from unknowing persons may also ease matters for those in the know...” (Goffman, [1963] 1986, p.102). Via the medical and fashion industries, mastectomized women are culturally encouraged to perform a discourse of concealment (Wilkinson, 2001, pp 271-272).

Hochschild’s approach to emotion management and emotional labor will help to analyze how women who feel most comfortable without a breast prosthesis in place, may, in fact, be forcing themselves to place one (or two as the case may be) on their post-mastectomy chests, no matter how physically, psychologically or emotionally uncomfortable, or perhaps even painful this may be. Motivated by ‘thoughts of others’ and not wanting to make others in their company feel uncomfortable or awkward, they instead will take on the emotional labor (Hochschild, 1983, p. 7) and physical labor of the discomfort and awkwardness.

Swidler introduces her inquiry and analyses of how humans “...make use of culture...” and “...what they use it for” (Swidler, 2001, p. 71). Coining the term “cultured capacities” a person uses culture in the formulation of the self – in constructing, maintaining and refashioning it, which are the “cultured capacities” that make up a social “actors’ basic repertoires for action” (Ibid, p. 71). These “repertoires for action” are initially referred to by Swidler as “tool kits” which can then be chosen and constructed as “strategies of action” -- in order to deal with an issue or problem (Swidler, 1986, p. 273).

In the context of breast cancer and mastectomy in this thesis, I ask: “Can cultured capacities be used as a problem-solving strategy by mastectomized women to deal with their chests that become void of breast tissue due to breast cancer?” This concept will be explored and employed as a tool of thematic analysis in this section as well. It is essential to keep in mind Swidler’s belief that “...individuals maintain cultural capacities for varied strategies of action which they mobilize differently in different situations” and that “...the cultural influences individuals and groups carry into new situations are those that form their capacities for action...” (Swidler, 2001, pp 83-84).

Mahalik et al.’s study is also employed in this thesis in order to assist with thematic analysis of media interviewees’ media interview data regarding the Norms of Feminine Appearance category. This body norm category and several others will be introduced further on in this thesis work. This research team developed a tool to assess and measure women’s conformity to various traditional feminine norms present in dominant Euro-American culture (white, middle, and upper class, heterosexual). They define “conformity to feminine norms” as “adhering to societal rules and standards about how to be feminine and is demonstrated in the individual woman’s behaviors, feelings, and thoughts” (Mahalik et al., 2005 p. 418).

This work draws on data from media interviews conducted with women diagnosed with/or having the genetic risk of breast cancer, by various media interviewers in multi-media -- published and available in the public domain on the Internet, such as newspaper, magazine, organizational and dot.com websites, online videos, podcasts and documentary film. Each media interview has been chosen for its clear stance according to the three dominant body norms I have laid out in this thesis: Norms of Feminine Appearance, Norms of Body Part Replacement and Norms of a Healthy Body.

The sample is made up of 14 women and includes those who have undergone primary breast cancer treatments such as mastectomy surgery or prophylactic cancer risk-reducing breast removal, and in some cases, treatments to decrease the risk of recurrence – called adjuvant therapy. Some of these therapies could include chemotherapy, radiation, hormone therapy, immunotherapy, and targeted therapy (Mayo Clinic. Org, 2019).

The media interviews were conducted within diverse public media, with these 14 women from various age groups ranging between their 30's to 60's, different nationalities, gender identities, as well as racial, ethnic, socio-economic, and educational backgrounds. According to Allmark, 2004, these social factors “are likely to be markers for significant cultural differences. These differences may be of great importance for the social phenomena studied by qualitative research” (p. 188). Some have had both breasts removed in a bilateral mastectomy, and others just their single malignant breast removed. Some had had breast reconstruction, several had eventually had their implants removed (explanted) for various reasons; a number of others had never been reconstructed and decided not to have reconstruction from the beginning.

The media interviews were conducted by various media interviewers working in popular and multi-media; all are published and available in the public domain on the Internet, such as newspaper, magazine, organizational and dot.com websites, online videos, radio podcasts, television and documentary film. I have profiled as much diversity of social positioning and categorizations that I was able to find at the time of researching and writing this work.

### **Description of the research process involved in how I found these 14 media interviews of the women in my sample:**

After I discovered the initial ‘going flat’ article (October 2016) in the *New York Times* and had decided on this as my thesis topic, I used Google to conduct monthly to twice-monthly Internet searches for women’s post-mastectomy narratives that satisfied the diversity variables I was looking for. Between 2016 and 2019, I eventually gathered a sample of 14 when my diversity criteria were satisfied. I also used my judgement and took into account my time and number of pages constraints vis-à-vis preparing a master’s thesis. In the end, 14 proved to be a manageable number to use, in order to undertake the thematic analysis method on the media interview data, as well as these data’s ability to provide meaningful patterned results.

This goal of diversity also extended to accessing media interviews from a variety of mass media sources. These included print media newspapers and magazines that also appear in

electronic format online, film in the form of the documentary and video genre, the broadcast medium for the genres of radio and radio-podcasts and television, as well as the Internet genre in the format of the website. This was undertaken with the hope of accessing different and nuanced facets of their narratives by way of a variety of public media genres, that capture such things as voice, expressions of emotion, and gestures.

Thematic analysis relating to my research questions, and three central dominant body norms was undertaken in analyzing the media interview content. Thematic analysis of this qualitative data in some cases but not all revealed some general themes. These related to reasons for making a treatment choice, interactions and communication with health care professionals regarding treatment choice, as well as various physical and emotional outcomes regarding the treatment choice or perceived lack of agency/choice -- or what was viewed by some respondents as a prescribed paternalistic decision. A detailed analysis is written after each woman's media interview.

Due to privacy laws and the Canadian Research Ethics Board ethical concerns and legalities relating to them, ([www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca): Article 10.3, accessed in 2018) I have excluded using online forums, Internet chat rooms, self-help groups with restricted membership, blogs and social media of any type -- including Facebook groups and closed Facebook groups in this thesis. According to Article 10.3, there is a "much higher...privacy expectation" of people posting to these sites. Although these digital sites are ostensibly "publicly accessible," nevertheless, the posters' "identifiable information" on these "publicly accessible digital sites, and the actual data content they post is not for larger public consumption. In these cases, the concept of "a reasonable expectation of privacy" needs to be considered and reviewed via a research proposal to a Research Ethics Board.

In the final analysis, dealing with the usage of data from online forums, Internet chat rooms and self-help groups with restricted membership and the like, can encompass a mix of delicacy, complexity, and thorniness -- with multiple variants of grey at play. Article 2.2 ([www.pre.ethics.gc.ca](http://www.pre.ethics.gc.ca), accessed in 2018), states that "Research that relies exclusively on publicly available information does not require Research Ethics Board review when: a. the information is legally accessible to the public and appropriately protected by law; or b. the information is publicly accessible, and there is no reasonable expectation of privacy."

The majority of the going flat and flat movement women who used to participate in online forums have now moved over to closed, restricted membership Facebook groups, identifying as support and advocacy groups. A primary function of these closed Facebook groups stated to group members is to offer privacy – a ‘safe space’ in which to express themselves, and the encouragement to accept one’s ‘new normal’ flat-chested body through the posting of selfie photos, which are shared in an accepting and ‘flat-positive’ light, all of which are designed to help with self confidence as well as emotional and psychological healing. Given these ethics and privacy issues, none of the content from these groups could, or would be accessed nor analyzed in any way, shape, or form.

In sociology, a norm is a “shared rule about acceptable or unacceptable social behavior” (American Sociological Association, 2019). In keeping with this sociological context, the human body is expected to “fit” into specific “socially prescribed categories” which are then enforced by myriad institutions, all vying for power, influence, and control over the human body and its behaviors (Malacrida & Low, 2008, p. 124; Foucault, 1986 (1978). Dreger (2004) introduced the concept of shared rules based on body anatomy. She maintains that although they are often left silent, these unspoken rules send out a powerful message to all owners of human bodies -- “... normative ideas of what a body ‘should be’...” These parameters of ‘normal’ “have been formally and informally sanctioned across eras and cultures” (Malacrida & Low, 2008, p. 124). Hardin et al. ’s research on body norms yielded results asserting that “Body norms are not a single or universal set of values.” Instead, they have many “cultural influences” which can include such variables as “global health, local community members, and global media” all interacting “to create a complex landscape of contradictory norms” (Hardin et al., 2018, p. 285).

To undertake this thesis, I researched popular media sources for pertinent media interview data that related directly to my research topic and questions. I selected and then analyzed the media interview content of each media interviewee using thematic analysis based on my main research questions regarding motivations for ‘going flat’ and ‘living flat’ -- and three central body norms used in a socio-cultural context. Each body norm will be defined, described, and explained as a tool of analysis vis-à-vis ‘going flat’ and ‘living flat.’ The three I have chosen are the Norm of Feminine Appearance, Norm of Body Part Replacement, and Norm of a Healthy Body Appearance. I chose to analyze the media interview data based on these particular norms because I believe that they will be helpful in providing some valuable insights into what

motivated these media interviewees to reject breast reconstruction and the wearing of artificial breasts following mastectomy. Broad-based criteria included participants who identify as females with natural biological breasts, who have been diagnosed with breast cancer or deemed a high risk for developing breast cancer and have undergone breast cancer surgery, either as a primary treatment or on a preventive-prophylactic basis.

Each woman's media interview was also selected based on having a distinct situational stance vis-à-vis one of three different dominant body norms: Norm of Feminine Appearance, Norm of Body Part Replacement and Norm of a Healthy Body Appearance. Sometimes their positions overlapped with one or more norms. Some of the women interviewed started their breast cancer treatment journeys with a clear position on reconstructive implants, prostheses, or 'going flat-living flat' – no prostheses. However, in some cases, their positions changed over time, due to a variety of variables and circumstances.

## **MEDIA INTERVIEWS and Thematic Analysis of Data**

*Montreal Gazette.*

**Fidelman, C. (2017). "BRA day at MUHC promotes awareness about post mastectomy breast reconstruction."**

**Last Updated: October 16, 2017.**

### **Reconstruction**

#### **Deneise**

Early childhood educator Deneise (Fidelman, 2017, *Montreal Gazette*) is a married black woman living in Montreal who was diagnosed with unilateral breast cancer in 2014 at the age of 51. Her family history included her mother's breast cancer death years before. Although her case was categorized as 'early-stage' with no metastasis detected, a lumpectomy failed to remove all evidence of local cancer cells. Two options were put forth by her physician: a total mastectomy by a breast surgeon, with reconstruction performed by a plastic surgeon taking place during the same surgery time slot immediately after the breast amputation – or undergo a 'partial' mastectomy without reconstruction.

Deneise recounted that years ago her friend had had breast cancer surgery when reconstruction was not an available option – commenting that this friend had always "regretted (not having) it":

You lose a part of yourself and it's not like a cut. You heal, but it doesn't grow back.

Of the two choices presented to her, she ultimately took the mastectomy with immediate reconstruction option. The timeline involved in her procedure from start to finish was over one year, along with a later completion of a nipple reconstruction.

I wasn't aware of reconstruction when diagnosed, but luckily I had a surgeon who could direct me. I really feel thankful. I can fit in my bra, I don't need to pad, it's part of me rather than something I have to do (to pad her bra) daily (just) to wear a T-shirt. Reconstruction was (a) better plan for me. It helped me with my recovery, it really helped with my feminine identity.

Some of Deneise's breast cancer knowledge came from her mother's death from it, her friend's sense of regret at not having the chance to receive reconstruction for her lost breast, and from her doctors. Cromptvoets' research parallels this finding in her 2006 work, as she traces the sources and ways that breast cancer knowledge is constructed -- as she reports that "Understandings of breast cancer derive from women with breast cancer, medical specialists, breast cancer organizations, and corporations who benefit financially from breast cancer treatment" (Cromptvoets, 2006, p. 144).

Along with Deneise's realization that a breast is a body part that does not "grow back" speaks to current Western dominant cultural hetero-normative tropes whereby, according to Kasper's research, suggests that a woman's breast loss is socially constructed within a socio-cultural context -- one that conveys an ideology that fear of breast loss and subsequent threats to her body image and notions of femininity can be equal to or even trump the fear of being ill or dying from breast cancer (Kasper, 1995). Why is this?

Kasper proposes that it is due to how the socio-cultural matrix has historically established a hard-wired connection between "women's appearance and self-worth." This insight implies a pseudo-social fact, that "a woman is only as good as she looks" -- society calculates survival and cosmesis of equal value regarding a woman's true worth. Although breast cancer and subsequent surgery and breast loss manifest as embodied physical threats and even death of a woman's body from cancer, simultaneously the threat extends to the immaterial mind and spirit -- and to the "loss of the self as well... The social and cultural antecedents to a breast cancer crisis powerfully prefigure the difficulties women face when breast cancer occurs" (Kasper, 1995, pp 208, 209-210). As Butler professed, these are essentially pre-ordained and prescribed hetero-normative responses to having breasts (and subsequent breast loss), which women then perform and enact, even through a life-threatening breast cancer crisis (Butler, 1999 [1990]).



Kasper's qualitative study found that the "resolution of a breast cancer crisis" did not depend on breast reconstruction as an essential element. She postulates that the Western medical model of disease and the medicalization process itself then wants to provide "the medical care to redress the loss it has helped to create" (Kasper, 1995, p. 197).

Dr. Tassos Dionisopoulos (Fidelman, 2017, *Montreal Gazette*), the Jewish General Hospital's chief of plastic surgery in Montreal explains that due to increased understanding of the genetics-breast cancer link, there has been a marked increase in women seeking to decrease their risk of breast cancer development by having prophylactic bilateral mastectomies. Also contributing to this uptick in mastectomies is the demographic of young women diagnosed with unilateral breast cancer deciding to have bilateral mastectomies as a precautionary action. Dionisopoulos attributes this reconstruction trend to a momentum stemming from "patients and breast cancer advocacy groups."

Although not explicitly mentioned by Dionisopoulos, the dominant norm of breast-beauty discourse and symmetry and the aesthetics of symmetry also figure prominently in women's decisions to have both breasts removed when just one has been identified to be cancerous. In other words, being uni-breasted presents a 'lop-sided' appearance, which is not pleasing to the eye in the classic Greek symmetry sense of beauty. Single-breastedness also presents practical, daily challenges to fitting into underwear and clothing, and makes the breast loss less amenable to camouflage strategies and therefore more noticeable as a visual, psychological and emotional "loss" both in the private and public spheres.

Having both breasts removed in one surgery also has the potential to make a bilateral reconstruction more appealing in the hope of receiving a fresh 'brand new set of mirrored breasts.' Additionally, the fact that when just one breast has had a lumpectomy or is reconstructed, the remaining breast almost always "requires" surgery as well, in order to have symmetrical breasts, where the plastic surgeon may "create" one new breast and modifies the remaining breast, with the goal of having two matching breasts of relatively equal size and shape (Somogyi et al., 2018; Breast Cancer.org, 2019). As per plastic surgeon Dr DellaCroce:

"Symmetry is nine-tenths of a quality reconstructive outcome. A reconstructed breast will reflect the artistry and technical talent of a skilled plastic surgeon, but it may not be possible to properly match it to your other breast without adjusting it as well" (Breast Cancer.org, 2019).

**Dr. TD:** Scars can be devastating. Sometimes the cure can be worse than the disease.

Although this can be the case for some women, many others may not feel this sense of devastation. This medicalized messaging relates to several of Kasper's research findings. The fact that there is no homogeneity in mastectomized women's responses to breast amputation will be discussed in subsequent sections of this work.

Deneise's plastic surgeon, Dr. Lucie Lessard, chief of Montreal University Health Centre's Division of Plastic and Reconstructive Surgery speaks of the initiative originating in Canada – started in 2011 by Toronto plastic surgeon Dr. Mitchell Brown, called Breast Reconstruction Awareness (BRA) Day hosted by the Canadian Cancer Society. The Canadian Cancer Society reports that Dr. Brown “saw the urgent need for improved breast reconstruction education, awareness and access. BRA Day was created to “Close the Loop on Breast Cancer” (Canadian Cancer Society, 2019). Financial sponsorship for the event is provided by a variety of sponsors, which include the Canadian Society of Plastic Surgeons, along with breast implant companies such as *Mentor* and *Natrelle*. Now, several years later, BRA Day takes place not only in some 25 communities across Canada but on a global scale as part of breast cancer awareness month. Lessard's areas of expertise include whole breast reconstruction “with the nipple when possible.”

**Dr. Lucie Lessard:**

...years ago...Many were not aware this option existed. We had a mission to try to educate women that it's not the end. When a patient catches a glimpse of herself in the mirror, she sees a whole person rather than a naked space, which for many is a painful reminder of the cancer. They can turn the page. It's very powerful for the woman, psychologically and emotionally.

Crompvoets' examination of women's personal experiences of breast reconstruction offers a multi-faceted view of lived experiences of reconstruction. Although her findings concur with what Deneise has said, the majority of her respondents – even though they initially viewed undergoing reconstruction as a means of restoring their “lost femininity, sexuality and normalcy,” realized that it was not having the actual, physical-surgical recreation of “breast mounds” on their chests that enabled them to feel feminine and normal again – it was the very practical aspect of the “elimination of the hassles of prostheses” (Crompvoets, 2006, p. 75). Deneise alludes to this reason as well when she says:

D: (*Living with one breast until expanded tissue was ready for the implant*)

I really feel thankful. I can fit in my bra, I don't need to pad it, it's part of me rather than something I have to do daily (just) to wear a T-shirt.

This sense of prosthesis fatigue and the daily maintenance work required is what Cromptvoets is referring to as one salient variable in women's motivations to seek breast reconstruction (Cromptvoets, 2006).

**Debra** *The Good Breast Documentary*: Wegenstein, B. (2016) and "The U.S. Breast Cancer Body in the Rising Age of the Mastectomy:" Wegenstein, B. (2017).

**Dr. Sheri Slezak**, Plastic Surgeon, Greater Baltimore Medical Center, Associate Professor of Plastic Surgery, University of Maryland. Her career in plastic surgery has spanned more than forty years. (*The Good Breast*, 2016):

**Dr. SS:**

One thing I've learned through all the years, is that a breast is a very subjective organ – and one woman can lose it and not think much more about it – another woman, it's devastating to lose it – and she will mourn for it for years.

**Debra** is a white, middle-class nurse in her early 50's and the mother of a 14-year old son who had a unilateral mastectomy with reconstruction. Of her own volition, as they are not a clinical requirement, she regularly visits her oncologist for checkups. During one such visit, she speaks about her breast loss and her realization that it has triggered "the idea of loss elsewhere in her life – her unhappy marriage, the loss of her fertility, and that she never was able to have a daughter" (Wegenstein, 2017, pp 20-21).

**Debra:**

After my mastectomy I needed to have the reconstruction right away. I thought – well why do they hurry up with all of this? Why do you have to do it all at once? But it was important as I look back, to be able to have the bandage come off and to have a breast there.

For Debra, her initial feelings of being rushed into an immediate breast reconstruction appeared to puzzle and disturb her – as well as elicit some feelings of anxiety. She seemed confused as to whether having it done "all at once" was too overwhelming for her. The sequence of events, and the way she recounts them do not suggest she felt she had any agency in what happened to her body and when. The messaging Debra received from her health care professionals was that she

“needed” to have the reconstruction “right away.” Who was communicating this to her? Did she not feel she was able to direct the course and order of events herself, ask questions, get answers, make her own decisions regarding “if” and “when” she would have reconstruction? When she asks questions, she asks them to herself, but appears not to have verbalized them to her doctor or anyone involved with her care. When she uses the pronoun “they” and then “you have to,” she does not convey any sense of control in her own case. In retrospect, she describes it as “important” to have “a breast” in place on her chest when the bandage was removed. Even though she is an adult woman in her fifties and a nurse, her mode of communication is child-like – showing a lack of control or decision-making power in her breast reconstruction experience.

### **From Implant to Explant**

**Marianne & Thedra *CBS News*, March 12, 2017 “A Matter of Choice.” *CBS Sunday Morning*.**

In March of 2017, an American television news program held a feature group interview with six Caucasian women aged 34 to 51, who had undergone mastectomy for breast cancer, and chosen not to have reconstruction, nor to wear removable breast forms -- prostheses. The interviewer names this relatively new phenomenon, “going flat” (CBS News, 2017). The background information given on the program puts US breast reconstruction levels at 57% (citing the source as Cancer.org), as close to 60% of women who are “offered” reconstruction undergo it. (However, some are never offered it, as not all mastectomy patients receive referrals to breast reconstruction surgeons nor are eligible, for a variety of reasons reported in other sections of this thesis.)

Dr. Deborah Axelrod, a surgeon and Director of Clinical Breast Services at New York University Perlmutter Cancer Center was also interviewed in separate media interviews.

**Dr. Deborah Axelrod:** I think for us as surgeons – we feel that if we’re going to take a body part off, that we should then replace it with something that looks just as good.

This response speaks to the Western medical model of disease previously introduced and the role that the “surgeon as body mechanic” has been trained to play for centuries.

**Journalist-Interviewer Erin Moriarty in Voice-over:** She (Dr. Axelrod) says reconstructive surgeries have greatly improved and yet, she agrees that looking good can have some unexpected drawbacks.

**Dr. DA:** You know if you’re a stomach sleeper and you have an implant, it’s like sleeping on a Frisbee sometimes.

This revelation may have varying levels of significance for women going through the reconstruction decision-making process. Having this knowledge included as part of a standardized decision-making tool for women internationally would be an essential policy study to be considered by breast reconstruction policy makers. Are all women who need to make this decision being told this as a fact beforehand? Or is information like this being omitted by plastic surgeons, whereby women are being disempowered by not being given the facts they need to make informed decisions and give truly informed consent prior to their surgery?

**EM Voice-over:** Dr. Axelrod now regularly discusses the option of going flat with her patients. Is this something that has become a standard of care internationally, so women are given all their options in a non-biased, transparent fashion, or is the dominant medical discourse being upheld depending on the ideologies of the individual plastic surgeon?

**EM:** Do you think still, the majority of women will choose reconstruction rather than going flat?

**Dr. DA:** I do. Because it's the image of our bodies. We want to be whole.

This statement involves the dominant discourse of the Western medical practitioner. The norm of body part replacement. For some women being "whole" means reconstructing their breasts, for others it may not.

**EM Voice-over:** Marianne Duquette Cuozzo says that when she was diagnosed with breast cancer...she went from breast surgeon to plastic surgeon the same day. (Immediate reconstruction).

**MDC:** Oh, I wanted breasts. I wanted what I had. They did a beautiful job and I was very happy with them.

**EM Voice-over:** But Cuozzo, one of the estimated twenty percent (according to doctors) who suffer side effects, had infection after infection. So she decided, "*It was just -- Let's get them (the implants) out.*"

**Thedra Cullar-Ledford:** It's kind of a myth, you know -- They're going to pop 'em in, it's gonna be fine. They'll be great. It's a myth.

**EM Voice-over:** There's another myth, says Thedra Cullar-Ledford – that reconstructed breasts will feel real.

**MDC:** They feel like regular breasts to somebody else – to whoever (sic) is touching them – not to you – to a man perhaps or to whomever. They don't feel like real breasts.

**TCL:** Yeah, there's no feeling – there's no nipple – there's no sensation.

MDC confirmed that she *desired breasts* -- she states several times that she had *wanted* them -- that she had *wanted* what modern plastic surgery could do to replace the breasts she once had. She describes the doctors' surgical efforts as "*a beautiful job*" and her feelings of being "*happy*" with them. However, the specter of complications arose in her case in the form of recurrent infections. Eventually she decided to have them removed (called explanted). In spite of the two positive descriptors she uses -- *beautiful* and *happy* -- when another respondent TCL raises the issue of reconstructed breasts not feeling real to herself, as in her own subjective experience -- that they had no *feeling, sensation* and had no nipple, MDC concurs with TCL's assessment.

MDC distinguishes between the objective and subjective experience of the woman with reconstructed breasts and how they feel to her, and the person who may be touching the reconstructed breasts as objects of pleasure, when fondling them. MDC is quite direct when she says that they may "*feel like regular breasts*" to another person -- to "*somebody else*" but "*not to you*," to the *touchee* -- only to the *toucher*, the one who is doing the *touching* -- "*to a man or whoever*." MDC definitively concludes: "*They don't feel like real breasts*."

Regarding her own experience, TCL refers to several aspects of reconstructed breasts as a *myth* -- that they will *feel real*, that they will be *easy* -- in that the plastic surgeons will just *pop 'em in*, that they will be *fine* and that they will be *great*.

TCL's background experience with breast cancer, a double mastectomy followed by breast implants includes being told that having post-mastectomy implants was "standard" procedure after having a double breast amputation, so she agreed to the procedure. Almost immediately after having the implants her body reacted and gave her signals that it was "trying to get the implants out of me" -- as if her body was actively rejecting them. She describes being met with resistance from medical providers, to having them removed, but ultimately she did have them explanted and now she is "living flat" (McAshan, Texas Medical Center, 2016).

In her *New York Times* article "Going Flat After Breast Cancer" Rabin states:

But some women say that doctors focus too much on physical appearance, and not enough on the toll prolonged reconstructive procedures take on their bodies and their psyches. Up to one-third of women who undergo reconstruction experience complications. A systematic review of 28 studies (Lee et al., 2009) found that women who went without reconstruction fared no worse, and sometimes did better, in terms of body image, quality of life and sexual outcomes. (Rabin, 2016)

Dr. Clara Lee, Associate Professor, Plastic Surgery, Ohio State University – who performs reconstructive surgery said:

That’s the dirty little secret of breast reconstruction: The risk of a major complication is higher than for the average elective surgery. (Rabin, 2016).



Clockwise from top left: Charlie Scheel, 48; Marianne Duquette Cuozzo, 51; Rebecca Pine, 40; Paulette Leaphart, 50.  
Béatrice de Géa for The New York Times

Figure 1: Screenshot from New York Times article: November 4, 2016  
“The Women Who Showed Their Breast Cancer Scars” By Roni Rabin

### Reconstruction as a Routine Choice

All of these respondents concur with doctors Uroskie & Colen, Dionisopoulos and Lessard, that having breast reconstruction following mastectomy for breast cancer has currently become a “routine choice” for women. Since the 1998 passing of the United States federal Women’s Health and Cancer Rights Act, all women undergoing mastectomy for breast cancer have the right to have reconstruction protected as a covered benefit procedure that cannot be denied due to its categorization as cosmetic or not medically necessary by their healthcare insurance plans.

However, being enshrined in the law does not guarantee that all women will have access to this surgery, as variables such as geographic location, type of health insurance plan, income and race/ethnicity continue to be access influencers (Offodile II & Lee, 2018). In Canada, it is a covered benefit by provincial healthcare plans (but the scope of coverage may vary by province). However, access can also be limited by various dependent variables such as geographic location far away from major hospital centers, race/ethnicity, education level, socio-economic status, availability of operating room time and trained breast reconstruction surgeons (Canadian Institute for Health Information, Breast Cancer Surgery in Canada, 2012).

Deneise and Debra's media interview data concurred with doctors Uroskie & Colen, Dionisopoulos and Lessard that living without a breast in this epoch is not necessary with the reconstruction medical expertise and technology that is now available. Deneise felt thankful that her surgeon suggested the surgery and made it available to her; that it was a better situation for her; that it helped her with her overall recovery. Debra ultimately appears to communicate her agreement with the importance of having reconstruction as a valid medical-surgical choice made available for her as well, when she describes it as important to have a breast in place on her chest when the bandage was removed.

On the other hand, regarding Uroskie & Colen's assertions that a woman "can exist with a recreated breast that looks and feels like very natural (sic)" – MDC and TCL's responses did not show agreement with this statement. For them, their breast implants did not feel real – as if it were a "natural" breast -- to themselves, whose chests were the recipients of these implants, nor did their recreated implanted breasts have sensation. In both MDC's and TCL's cases, they also could not, as breast cancer surgical patients "comfortably realize" as claimed per Uroskie & Colen, that they could exist with a recreated breast; due to MDC's recurrent infections in her implants which ultimately necessitated their removal (explanting) and TCL's body's reactive rejection of her implants also ultimately necessitated them being explanted. Following these experiences, both women "went flat" at the end of their treatment trajectories, and are now "living flat." MDC states that "I did not choose to "go flat," going flat" chose me."



## **Reconstruction Information for Patients: Origins**

All of these respondents had medical information regarding breast reconstruction that originated with their physicians. Kasper also notes that the majority of her study participants reported that besides coming in contact with and viewing another woman's breast reconstruction, their physicians were the primary source of information for the procedure (Kasper, 1995, p. 214; Cromptvoets, 2006).

None of the respondents included in this thesis said they were given information on non-reconstruction, on wearing external prostheses, or going flat and living as a flat-chested, non-reconstructed or non-wearer of external prostheses as a choice – as a viable way to deal with their breastless chests, post-mastectomy. Cromptvoets, 2003, 2006; Kasper, 1995; Young, 2005 and Offodile II & Lee, 2018 all speak to these issues. In Kasper's study, only one respondent out of 16 who received reconstruction was "unequivocally positive about the role breast reconstruction played in her recovery and return to normal living" (Kasper, 1995, p. 215). The majority of Kasper's participants "stated that their physicians either suggested or promoted reconstruction as important to their recovery and well-being" (Ibid, p. 214). The Canadian Cancer Society, 2019 web page on reconstruction and BRA day states a similar ideology and message:

Reconstruction allows women to improve their quality of life and move forward from their journey through cancer with a renewed sense of wellbeing. Breast reconstruction helps close the loop on a woman's experience with cancer.

The majority (12 out of 16) of Kasper's study participants felt ambivalent about their breast reconstruction experience and its place in their breast cancer recovery process. Their reactions ranged from being somewhat positive to uncertainty or indifference to disappointment, and some had entirely regretted their "choice" to reconstruct. Kasper underscores her respondents' realization that reconstruction has its limitations – it was not able to "virtually replace the lost breast," as in reality it is "only a physical approximation of a female breast, one that has none of the sensory, sexual, or maternal capacities of the normal breast. In sum, its sole purpose is to appear to be what it is not" (1995, p. 215).

Young invokes the replaceable parts metaphor and refers to surgical breast reconstruction as the "ultimate in breast objectification" (Young, 2005, pp 94-95). She views the medical message of hope given to women, to assist them in imagining themselves "as good as new" after reconstructive surgery -- that has many women finding themselves "surprised and disappointed"

– that the reconstructed breast does not bear any similarity to the look and feel of their original breast organ (Ibid, p. 95). Referring to Lorde’s one-breastedness and her insistence on body authenticity, and her anger that uni-breasted women with breast cancer must hide their mastectomies behind prostheses, making their cancer invisible to society and each other -- Young asserts that “In a differently constructed culture, she might reconstitute her body identity and learn to love herself with one breast” (Ibid, pp 95-96). However, in the male-dominated culture, we currently live in, Young is not optimistic that this is possible at the time of publishing in 2005.

### **Norm of Feminine Appearance**

Grosz regards the body as a ‘site of social, political, cultural, and geographical inscriptions, production or constitution ... it is itself a cultural, the cultural product’ (Grosz, 1994, p. 23). Indeed, she points to the mythology of the fallacious argument regarding the existence of a pre-cultural natural body – ‘cultural inscriptions quite literally constitute bodies ... as such,’ which mold and sculpt our bodies in very concrete, distinct ways (p x). Further to this notion, Grosz is unequivocal in conveying her belief that “There is no ‘natural’ norm; there are only cultural forms of body, which do or do not conform to social norms” (p. 143). Viewing the body from the ‘Outside In’ – she “sees” it, courtesy of Foucault’s social constructionism, as a ‘social object, as a text to be marked, traced and written upon by various regimes of institutional power’ (p. 116).

The body image is a map or representation of the degree of narcissistic investment of the subject in its own body and body parts. It is a differentiated, gridded, and ever-changing registration of the degrees of intensity the subject experiences, measuring not only the psychical but also the physiological changes the body undergoes in its day-to-day actions and performances’ (Grosz, 1994, p. 83).

### **What is a feminine norm body image?**

Grosz gives us an historical overview of the notion of body image and the discovery of tools for dealing with conflicted feelings regarding one’s body image. Dealing with phantom limbs, phantomization, and prostheses “The treatment of war injuries seems to have provided the strongest stimulus to the exploration of anomalies of the body image” (Grosz, 1994, p. 64). Grosz introduces us to the concept of the body image referred to in Western medicine, as dating back millennia, starting in Egyptian antiquity. Other more modern body image milestones include the sixteenth-century medical-surgical pioneering experiences of French surgeon

Ambroise Paré, who gleaned his extensive experience with amputations, ligature and artificial limbs and eyes from treating war injuries.

Treating war injuries, the overwhelming majority of whom, if not all were male soldiers, appears to have ‘provided the strongest stimulus to the exploration of anomalies of the body image’ (Ibid, p. 64). Here again, we see androcentrism at the very genesis of a seminal work, this time on anomalies of the body image. Another common battlefield injury, namely brain trauma lesions, led to further research by British neurologist Sir Henry Head in the early 1900s. Along with Gordon Holmes, they developed the terminology that dealt with the idea of the body image, inventing descriptive nomenclature such as ‘postural model of ourselves’ or the ‘postural schema’ (Ibid, p. 65). The concept of a ‘body schema’ appeared in their 1911-12 work, whereby, due to ‘perpetual alterations in position, we are always building up postural models of ourselves, which constantly change’ (Ibid). A few decades later, Schilder would conceive the descriptor body image, its genesis materializing directly from following Head and Holmes’ research and writings (Ibid, pp 66-67).

Schilder, who studied under Freud, originated and in 1935 first wrote about the contemporary concept of a human body image in his work *The Image and Appearance of the Human Body*. He defines it as meaning ‘the picture of our own body which we form in our mind ... the way in which the body appears to ourselves’ (Schilder 1978: II quoted in Grosz, p. 68). His body image concept involved three dimensions: physiological, sociological, and, channeling his mentor-teacher Freud, also possessing emotional and libidinal facets. The social relation aspect of body image involves ‘the subject’s experience of its own body’ (as it) ‘is connected to and mediated by others’ relations to their own bodies and to the subject’s body’ (Ibid, pp 67- 68). ‘The body image can shrink or expand; it can give parts to the outside world and can take other parts into itself’ (Schilder 1978: 202 in Grosz, p. 80).

When Grosz speaks of psychoanalysis and psychical landscapes of the body, she concludes that ‘What psychoanalytic theory makes clear is that the body is literally written on, inscribed, by desire and signification, at the anatomical, physiological and neurological levels’ (p. 60). Also quite significantly, she states that ‘the body which it’ (psychoanalysis) ‘presumes and helps to explain is an open-ended, pliable set of significations, capable of being rewritten, reconstituted, in quite other terms than those which mark it, and consequently capable of re-inscribing the forms of sexual identity and psychical subjectivity at work today’ (Ibid, pp 60-61).

Although the different factions within feminism have attempted to reorganize and reframe the body, and their own bodies within society, it has been executed within an historically existing patriarchal framework, created for and by the androcentric-hegemony. The overwhelmingly negative socially portrayed representations perpetuated from that same flawed body evolution, do not serve women's sociological, psychological, emotional, or physiological needs to this day. '...women's body images are clearly different from men's and are modeled on lack and castration...' (Ibid, p. 73). Thus Grosz's hailing to feminist scholars of all stripes, the call to challenge and question – to create new theories for a 'corporeal feminism' – made from newly excavated, pristine unworked clay, by and for women – no longer androcentric but instead created from gynocentrism. 'Until women's bodies are inscribed and lived (by the subject and by others) as a positivity, there will always remain paradoxes and upsetting implications for any notion of femininity' (Ibid, p. 73-74). These sentiments are also echoed by Iris Marion Young's work (Young, 2005).

### **Referencing the Feminine**

A person born as a human female denotes a biological distinction of the sex that can bear offspring or produce ova, which can be fertilized by male sperm (Oxford Dictionary, 2019). A woman is "an adult human female" (Oxford Dictionary, 2019). Young references 'female' as "more to living out materialities of bodies" (Young, Introduction, 2005, pp 4-5). These "materialities" can be taken to mean such female bodily processes and experiences as female breast development, menarche and menstruation, pregnancy, giving birth, breastfeeding, and menopause (Ibid, pp 4-5).

Feminine refers to "having qualities or an appearance traditionally associated with women, especially delicacy and prettiness" (Oxford Dictionary, 2019). Young references 'feminine' as referring "more to gendered social conventions" (Young, 2005, Introduction, p. 4). The goal of Young's inquiries is her attempt to encompass the "social meanings of female embodiment" (Ibid, p. 4). By engaging in further development and clarification of Battersby's distinctions between 'female' and 'feminine,' Young reconstructs "feminine" to signify "a relational position in a dichotomy, masculine/feminine, where the first is more highly valued than the second, and where the second is partly defined as a lack with respect to the first" (Ibid, p. 5; Grosz, 1994).

Young's conception of the feminine is "also as a set of normatively disciplined expectations imposed on female bodies by male-dominated society" (Ibid, p. 5

Normative femininity detaches persons who fall under its disciplines from expressions or enactments of power and authority. Disciplines of the feminine, finally, aim to mask or subordinate the raw facts of embodiment, to make the body "pretty" by constraining straining fluid flesh, masking its organic smells with perfumes, painting skin, lips, eyes, and hair that have lost their nubile luster (pp 5-6).

This notion of "disciplined bodies" originally put forth in Foucault's *Discipline and Punish* (1977) has also been further developed and analyzed by King (2004). She suggests that "gender, specifically femininity, is a discipline that produces bodies and identities and operates as an effective form of social control" (King, 2004, p. 29). However, King underscores an overarching and salient point, the same one made by Foucault in his subsequent works (Foucault, 1978 (1998) and 1991) -- that human resistance and agency be considered possible (Gimlin, 2002). According to King, Foucault contended that 'resistance exists wherever the duality of normalization and domination occur. Power is never total, uniform or smooth but shifting and unstable; if it is exerted on 'micro levels' it can be contested on micro levels; there is "no single locus of great Refusal" but a "plurality of resistances"' (King, 2004, pp 36-37, quoting Foucault, 1998, pp 95-6).

### **Mahalik et al. Conformity to Femininity Norms Inventory (CFNI)**

Mahalik et al. 2005 developed a tool to assess and measure women's conformity to various traditional feminine norms present in dominant Euro-American culture (white, middle, and upper class, heterosexual). They define "conformity to feminine norms" as "adhering to societal rules and standards about how to be feminine and is demonstrated in the individual woman's behaviors, feelings and thoughts" (Mahalik et al., 2005 p. 418). If a woman conforms to certain feminine norms, and her belief system is invested in the significance of the norm – she then is either able to enact the feminine norm and garner positive feelings within and about herself, such as "pride" --which is direct emotional feedback related to her conformity behaviors. On the other hand, if she is unable to believe in, nor enact the particular feminine norm expected to be manifested in her behavior, this may elicit internalized negative feelings such as its emotional norm pair (De Courville, 2011), which is "shame" due to her nonconformity. Mahalik et al. take the meaning of the term nonconformity to feminine norms as: "...defined as not adhering to societal expectations for what constitutes femininity" (Ibid, 2005, p. 418).

Citing Brown, 1998 and Mahalik et al., 2003, Mahalik, et al., 2005 maintain that the feminine ideologies originating from the dominant Euro-American, middle-to-upper class, heterosexual culture (and by extension North American-wide hegemonic culture) which underpin and are embedded in Euro-centric norms of femininity, are reputed to be “the most pervasive and powerful” in American society (Ibid, p. 418). These authors are convinced that these hegemonically-constructed prescribed standards of femininity most surely must impact the dominant group members, “as well as every other woman in U.S. society who is held up to those standards and who experiences acceptance or rejection from the majority culture, in part, based on adherence to the powerful group’s femininity norms” (Ibid, p. 418).

Mahalik et al. undertook several steps while constructing their Conformity to Femininity Norms Inventory (CFNI), which included literature reviews on American-based traditional feminine norms and several stages and phases of focus groups and surveys. Their results captured 8 factors which these researchers put into their Conformity to Feminine Norms Inventory and labeled them as: “(1) Nice in Relationships; (2) Thinness; (3) Modesty; (4) Domestic; (5) Care for Children; (6) Romantic Relationship; (7) Sexual Fidelity; (8) Invest in Appearance” (Ibid, p. 421).

Their research team retained corresponding listings of behaviors, feelings, and thoughts consistent with the feminine norms (FN) that women are expected to engage in -- these are specific behaviors/actions that need to be enacted in order to manifest a particular feminine norm (FN) as defined by these actions/behaviors, for example: “(1) FN= develop friendly and supportive relationships with others (in order to be) (1) Nice in Relationships (1) Thoughts and Feelings: It is important to let people know they are special; (2) FN= pursue a thin body ideal (to be/have) (2) Thinness (2) Thoughts and Feelings: I would be happier if I were thin; (3) FN= refrain from calling attention to one’s talents or abilities (in order to have) (3) Modesty (3) Thoughts and Feelings: I always downplay my achievements, I feel uncomfortable being singled out for praise, There is nothing wrong with bragging (reversed/nonconformity) 8) FN= commit resources to maintaining and improving physical appearance (in order to) (8) Invest in Appearance (8) Thoughts and Feelings: It is important to look physically attractive in public; I’d feel superficial if I wore make-up (reversed/nonconformity); I never wear make-up (reversed/nonconformity)” (Ibid, pp 421, 424).

The authors clarify that their study results do not indicate that there are a finite number of just 8 feminine norms operating within the dominant culture in America. They concede that there are, of course, other feminine norms existing within the United States' dominant culture that were not captured by their "measure development process" and, as well, they did not identify "other feminine norms from other cultural groups" located internationally to use in their inventory (Ibid, p. 424). For this paper, (8) Invest in Appearance, and FN= commit resources to maintain and improve physical appearance will be dealt with and used as a tool of analysis for Thematic Analysis of the Body Norm of Femininity. (3) Modesty and FN= refrain from calling attention to one's talents or abilities may also be used where appropriate.

This study also discovered that the Invest in Appearance FN related negatively to women's self-report of a strong commitment to positive social change that addresses societal inequities. Women who were more likely to speak up about their accomplishments garnered a low score on Modesty as well as a low score on Invest in Appearance. These women were less likely to focus on their physical appearance and were more likely to report higher levels of feminist identity (p. 429). Mahalik et al., utilize Downing and Roush's (1985) five-stage model to describe and define women's feminist identity development: 1. Passive Acceptance – reflects acceptance of traditional European American, North American, gender roles, beliefs that men are superior to women, and that these roles are advantageous. 2. Revelation – in response to a crisis or crises that lead women to question traditional gender roles and to have concomitant feelings of anger toward men. Sometimes women in this stage also feel guilty because of how they may have contributed to their own and other women's oppression in the past. 3. Embeddedness-emanation – reflects feelings of connection to other women, cautious interactions with men, and development of a more relativistic frame of life. 4. Synthesis – is when women develop a positive feminist identity and are able to transcend traditional gender roles. 5. Active commitment – reflects beliefs that men are equal to women but not the same, and reflects a strong commitment to positive social change that addresses societal inequities. (Mahalik et al., 2005 p. 425). (Cited by Mahalik et al.: Bargad and Hyde, 1991; Downing and Roush, 1985; Fischer et al., 2000; Moradi, Subich and Phillips, 2002).

It has been well established through numerous studies that women's levels of body dissatisfaction are much higher than men's. This gender inequity also transfers over to women's concerns regarding their physical attractiveness being more pervasive among girls and women

than in boys and men (Bordo, 1989; Gimlin, 2002; Mintz and Betz, 1986, Worell and Todd, 1996 cited by Mahalik, et al., 2005, p. 429). Mahalik, et al., report that their prediction of finding “rigid internalization of feminine norms for appearance” – FN of Be Thin and Invest in Appearance, “...evidenced by high levels of conformity to these norms” – were associated with “higher levels of eating disordered behavior, negative body image, and preoccupation with weight...” (Ibid, p. 429).

These clusters of body dysmorphic-like ideation among women, such as women’s existing levels of body dissatisfaction, concerns about physical attractiveness, and negative body image demonstrate the level of pre-existing body issues many women have, in bodies that are considered in a state of normal health. When a breast cancer diagnosis and breast amputation is superimposed on top of those pre-existing body issues in some women, the outcome presents more challenges for them than for others, to maintain their feminine body image equilibrium.

Mahalik et al., suggest their CFNI could be used as a research tool to examine complex, multi-dimensional ways that women experience and respond to femininity issues in their lives. Given this, breast cancer and mastectomy would undoubtedly be considered a femininity issue and a life-threatening health, as well as an identity crisis that women, unfortunately, experience and have no choice but to respond to, and cope with in their lives. Therefore Feminist Identity issues will also be looked at in my analysis of this dominant body norm category.

They also suggest that the CFNI would be useful in looking at what benefits and costs are at play for an individual woman and others, to conformity (and the feelings of pride conforming may elicit) or nonconformity (and the feelings of shame nonconforming may elicit) to an array of FN femininity norms. Another permutation of this pride-shame dichotomy needs to be examined as well – the existence of the pairing of pride with nonconforming – this is made manifest when a woman who goes flat and lives flat subsequently feels, exhibits and verbalizes her sense of flat pride. In the case of this paper, women’s health-related behaviors and decisions relevant to their post-mastectomy chests in terms of reconstruction or no-reconstruction (‘going flat’), wearing prosthetic breasts, having ‘flat closure’ and ‘living flat’ will also be used in this section to examine and analyze via thematic analysis, the norm of feminine appearance.



## **Norm of Feminine Appearance: Media Interviews and Thematic Analysis of Deneise: *Montreal Gazette*, 2017**

Reconstruction was a better plan for me. It helped me with my recovery, it really helped with my feminine identity.

Deneise expresses the fact that reconstruction helped her with her recovery. It is unclear what the word recovery encompasses for her, but she does directly use the word helped again, to reference very clearly, that breast reconstruction helped with her feminine identity. One interpretation of this would be that having her amputated breast reconstructed, facilitated her feelings of being a two-breasted or whole woman again— as Dr. Debra Axelrod (CBS News, 2017) expressed it, as to why women would choose reconstruction over going flat:

### **Dr. DA:**

Because it's the image of our bodies. We want to be whole.

Deneise and Dr. DA both express a version of the Feminine Norm (8): Invest in Appearance. 8) FN= commit resources to maintaining and improving physical appearance (in order to) (8) Invest in Appearance (8) Thoughts and Feelings: It is important to look physically attractive in public. Looking physically attractive in public may also be interpreted as an extension of being whole, having a female body image that is complete (whole) with two breasts, and therefore is seen as socially acceptable and attractive in its feminine appearance.

Breast reconstruction can be seen as a cultured capacity of action that has been mobilized by Deneise in her new situation of breast cancer and mastectomy. Deneise is conforming to the FN of Investing in Appearance has elicited a feeling of pride in herself and her feminine appearance. While attending BRA day as a reconstruction model for other women scheduled for breast cancer surgery to look at and talk to, she spoke to one such woman:

### **D:**

She was devastated. I was able to speak to her – it was healing and comforting to her. Reaching out is important. I feel it's the one thing I can do, even if it's only for one person.

Deneise carried the cultural influence of her sense of femininity that breast reconstruction technology gave her into her new situation of breast cancer and mastectomy, and as a role model at the BRA day event.

## **Doris**

**Doris:** *The Good Breast Documentary*: Wegenstein, B. (2016) and “The U.S. Breast Cancer Body in the Rising Age of the Mastectomy:” Wegenstein, B. (2017).

After a previous botched and disfiguring lumpectomy for a breast cancer diagnosis a few years ago, Doris visits breast oncology surgeon Dr. Schnaper and requests a (prophylactic) double mastectomy and then breast implant reconstruction from plastic surgeon Dr. Slezak. Wegenstein reports that Doris was sexually abused by her grandfather for a five year period during her childhood – and that “Becoming a character in a documentary film has been a trigger for her to make the connection between her body image issues and her abusive past” (Wegenstein, 2017, p. 18). When asked by Dr. Schnaper why she wants to have a double mastectomy, if it is to feel secure, Doris answers:

### **Doris:**

It’s a mix Dr. Schnaper. I do want to feel... I’m a girly girl...I’m very feminine and I want to look as close to possible of being that person.

Doris has the bilateral mastectomy and pushes to have the largest sized implants possible – going from her original 140 grams to 400 grams, because Doris wants cleavage “more than anything” (Ibid, p. 18). Dr. Slezak tells Doris that in the end, her skin is not strong enough to accommodate such a large sized implant, due to being damaged from prior radiation treatments. Eventually Doris has repeated infection complications in one of her implants and has it removed.

### **Dr. Slezak:**

When she (Doris) first came, her goal was to get rid of her breasts, to give herself the lowest chance of breast cancer she could. Somehow in her journey, that’s changed to --- nothing about breast cancer -- but to: “I want these specific BIG BREASTS” – and that’s not the purpose.

Doris is now wearing her implant, now explanted, as an external prosthesis in her bra.

### **Doris:**

This is a pain. This is a royal pain. I want to be attractive – I want to be normal. I want to be that confident girl I’ve always been my entire life. And now I feel like I’ve wavered from that person.

Without her prosthetic breast implanted internally due to repeated infection complications, Doris is forced to confront wearing her silicone implant as an external prosthesis tucked inside her bra.

She expresses anger and frustration at this unwanted reality. Living her life in this situation has left her feeling that she is no longer attractive, normal, nor a “confident girl.” Doris’ identity and self image of being a woman who is “attractive,” “normal,” and “confident” rely on her having “big breasts” (as per Dr. Slezak), reconstructed with internally placed implants. She also equates being a “girly girl” and being “feminine” to having 400 gram implants that will give her cleavage. At this time, Doris appears to be operating from a position influenced by dominant norms of femininity and is not able to consider or utilize any new cultural tools to deal with her altered body appearance as a result of breast cancer surgery.

### **Paulette**

*The New York Times*, October 31, 2016

**Rabin, R. (2016). “‘Going Flat’ After Breast Cancer”**

**[www.nytimes.com](http://www.nytimes.com)**

**Paulette** is a 50 year-old African American woman from New Orleans, who, after a double mastectomy for breast cancer, and unable to undergo breast reconstruction due to a clotting disorder – “went flat.” “The nascent movement to ‘go flat’ after mastectomies challenges long-held assumptions about femininity and what it means to recover after breast cancer” (Rabin, 2016).

**P:** “Breasts aren’t what make us a woman” (New York Times, Rabin, 2016).

I'm still beautiful, I still turn heads even though I don't have breasts. It doesn't make me less of a woman. I'm a girly girl. I like getting dressed up, putting on makeup and everything else, but I refuse to allow one standard definition of beauty to exist in my household. That sets us all up for disappointment when things change. Regardless of what we look like, we should be celebrated. (Interview with Graham, 2016, [www.espnW.com](http://www.espnW.com))

8) FN= **commit** resources to **maintaining and improving** physical appearance (in order to) (8) Invest in Appearance (8) Thoughts and Feelings: It is important to look physically attractive in public. Looking physically attractive in public may also be interpreted as an extension of being whole, having a female body image that is complete with two breasts, and therefore is seen as socially acceptable and attractive in its feminine appearance. Paulette’s statement rejects this dominant cultural hetero-normative ideology within her statement that -- Breasts aren’t what makes us a woman. She is a nonconformer to this specific expectation of femininity.

Paulette was unable to have her breasts reconstructed following a bilateral mastectomy for breast cancer due to a physiological health condition, which made her surgery risks far too great. This could be considered going flat by default, as the reconstruction option was not a medical-surgical possibility for her. Now she is “living flat” without breasts. She walked topless, showing her mastectomy scars and flat chest during her public walk, from Mississippi to Washington DC to raise awareness of the financial hardships faced by cancer patients. Paulette was nonconforming to the FN of Investing in Appearance. She rejected the thought and feeling that it is important to look physically attractive in public. Paulette’s topless awareness march became a source of pride for her, and she rejected feelings of shame she was culturally prescribed to experience, feel and display.

Paulette appears to have gone through several stages of feminist identity development – particularly Revelation to Synthesis to Active commitment, in response to her crisis of breast cancer, in which she questions and then transcends her gender role, when she decides to walk topless in public, and transitions to stage 5 of Active commitment – where she reflects a strong commitment to positive social change that addresses societal inequities by embarking on her awareness march to highlight the financial hardships faced by cancer patients.

She would score low on the FN of Investment in Appearance but high on Feminist Identity Development. This revelation would concur with Mahalik et al.’s discovery that the Invest in Appearance FN related negatively to women’s self-report of a strong commitment to positive social change that addresses societal inequities. Women who were more likely to speak up about their accomplishments, garnered a low score on Modesty as well as a low score on Invest in Appearance. However, as Paulette also identifies as a “girly girl” who enjoys “getting dressed up and putting on make up,” she contends that she can still feel “beautiful” and “no less of a woman” without having her breasts.

Going flat and living flat publicly, can be seen as a cultured capacity of action that has been mobilized by Paulette in response to her crisis of breast cancer, mastectomy without reconstruction. Paulette carried the cultural influence of the “nascent going flat movement” (Rabin, 2016) into her new situation of breast cancer, mastectomy without reconstruction, as well as a woman who had undergone Feminist Identity Development, and became a public role model in her independent march of awareness for the need for social change and equity for people with cancer.

**Samantha**

**Allure.com**

**Dispelling Beauty Myths: Mastectomy – Lifestyle**

**“This Cancer Survivor Dispels The Stigma That Breasts Equal Femininity” | Allure Video**

**| CNE 7/12/2017**

**Samantha Paige**

Samantha Paige is in her early 40's and already a thyroid cancer survivor, diagnosed when she was a college student at the age of 21 (Geller, 2017). Her mother received a breast cancer diagnosis in her early 30's. With this family history in mind, Samantha decided to get tested for the BRCA gene -- receiving a positive result. After becoming pregnant and having her child, she decided to undergo a prophylactic double mastectomy.

I was presented with the options of: “Here are the implants that most women get.” I remember there being a little whisper (inside me) of like, really, this is it? If doing nothing was presented it was certainly not presented without bias. And I don't recall it being presented.

Samantha describes her previous Southern California lifestyle as fully embracing the dominant Eurocentric-North American, heterosexual, feminine norm:

I wanted to be a good mother, I wanted to be a good wife ... Most women were blonde and had big boobs, and so I grew my hair out, I wore dresses, I stepped into this role fully.

After eight years with implants, Samantha decided (explicit reasons are not mentioned) to have them removed (explanted) in 2016. Her doctor explained that following their removal, she would be flat, as a “best-case scenario” or perhaps even concave. Upon making her decision, she said she replied confidently to her physician:

Yes, I want to be flat. I'm excited to be flat.

Samantha recounts certain responses she receives, now that she is living flat:

I had just gotten off my flight from L.A. and walked to go and hop in a cab. The guy turned around and he was sort of at first glance just said “oh I will be right with you sir.” I would say it probably happens at least once a month. It shocks me every time and makes me really stop and think – is it because I don't have boobs anymore?

This is how I'm meant to be. This feels as if this is me. Which is why I have so much cause for pause and thinking when I hear someone call me “Sir.” It's because I've never

felt more feminine. I feel more like a woman (laughs) than ever before, without my breasts.

My name is Samantha Paige and I'd like to dispel the myth that breasts equal femininity.

Samantha appears to have received her double breast implants by default, which also appears to be a common theme amongst many of the respondents cited in this thesis. Describing her previous years in Southern California, Samantha describes and expresses a version of the stereotyped trope of the "California Girl" image of the Feminine Norm (8): Invest in Appearance. 8) FN= **commit** resources to **maintaining and improving** physical appearance (in order to) (8) Invest in Appearance (8) Thoughts and Feelings: It is important to look physically attractive in public. Looking physically attractive in public may also be interpreted as an extension of being whole, having a female body image that is complete with two breasts, and therefore is seen as socially acceptable and attractive in its feminine appearance.

Breast reconstruction can be seen as a cultured capacity of action that had initially been mobilized by Samantha, albeit by default, in her new situation of positive BRCA1 genetic risk test results and prophylactic mastectomies. Samantha's conforming to the FN of Investing in Appearance, initially allowed the results of her preventive double mastectomy to be "invisible" in her everyday socio-cultural world and could perhaps have elicited a feeling of pride in herself and her feminine appearance, because she "fit in" with the Southern California Girl ideal body image at the time, along with being the ideal wife and ideal mother image.

Eventually, after her explant eight years later and subsequent going flat and living flat – not trying to camouflage or hide her flat-concave chest with external prostheses or accessories and clothing, Samantha discovers that she is "excited to be flat," and that "*This feels as if this is me.*" She feels shocked and puzzled when she is called "Sir" out in public, when subjectively, she has "never felt more feminine" – "I feel more like a woman than ever before without my breasts."

Samantha is now, at this eight years-later-stage, nonconforming to the FN of Investing in Appearance, but only in terms of displaying breast mounds on her chest. She rejected the thought and feeling that it is important to look physically attractive in public – but only in terms of displaying breast mounds on her chest. Samantha's display of a clothed, un-camouflaged flat chest in public became a source of pride for her, and she rejected feelings of shame and stigma she was culturally prescribed to experience, feel and display.

Samantha appears to have gone through several stages of feminist identity development – particularly Revelation to Synthesis to Active commitment to be a role model for the flat positive

movement. Although she receives feedback from the public domain in the form of being identified and being taken for a male, subsequently called “Sir” – although this shocks her, -- albeit a form of “punishment” for her nonconformity for “...not adhering to societal expectations for what constitutes femininity” (Mahalik, et al. 2005) -- Samantha does not say she wants to change her flat appearance in order to shield herself from these occurrences.

Going flat and living flat publicly, can be seen as a cultured capacity – a new tool that has been mobilized by Samantha in response to her crisis of a genetic threat of breast cancer. Having prophylactic mastectomies was a decision Samantha felt empowered to make herself, but in retrospect, undergoing the reconstruction definitely did not feel like a decision Samantha had any input on. She expresses the feeling that she had implants by default. Conversely, for her subsequent implants removal, going flat and living a public flat life, Samantha felt fully empowered to make these choices. Samantha carried the cultural influence of the “nascent going flat movement” (Rabin, 2016) into her new situation of having her breast implants removed and going flat, in order to live flat. She is also a woman who has undergone Feminist Identity Development, becoming a public role model for social change and the flat positive movement for women who have undergone breast surgeries for either the threat of breast cancer or a breast cancer diagnosis.

### **Norm of Healthy Body Appearance**

Once again to invoke Grosz -- who is unequivocal in conveying her belief regarding human bodies -- that “There is no ‘natural’ norm; there are only cultural forms of body, which do or do not conform to social norms” (1994, p. 143). However, can we put norms of private and especially public displays of a “healthy body appearance” into Grosz’s same ideological system?

The World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO Constitution, 2006). A person having a healthy appearance can also refer to a person being described as “healthy-looking” – as they appear “in good physical condition” (English Oxford Living Dictionaries, 2019). Regarding the concept of health – Saltonstall’s 1993 research led her to challenge some of the existing classic views, such as the medical model, that defined health as merely the absence of illness (p. 12). Saltonstall found that “the perceived physical body and body practices play a prominent role in the construction of other selves as healthy” (Ibid, p. 11). In other words, when

people view others as having a healthy body appearance, this notion is constructed by how they perceive certain aspects of other people's bodies and also these other people's body practices. The author referred to these cues as 'body insignia,' such as having "a good skin color and glow" or looking like they (others) are "in shape" (Ibid, p. 11). Saltonstall believes that "health actions are political actions enacted via the body which legitimate or challenge norms and ideas of the social body" (Ibid, pp 12-13); health actions of the individual body vis-à-vis challenging the norms and ideals of the collective population envisioned as a single, social "body."

Early twentieth-century nation-building, and the imperative of a metaphorical healthy nation, existing as a single body made up of the individual "healthy bodies" necessary to undertake this nation-constructing by "governments," was a common theme of this era (Bashford, 1998; Blum, 2008; Serlin, 2004). Before this, Foucault's original and influential milestone investigation of the history of human sexuality introduced the concept of "biopower," which developed during the mid-eighteenth to early nineteenth centuries. During this era, Foucault explains that the organization of power over life, no longer reigning down onto the social body from the crown, but from nascent "governments." This new power was in charge of "the administration of bodies and the calculated management of life;" defining biopower as "diverse techniques for achieving the subjugation of bodies and the control of populations" (Foucault, 1986 (1978), p. 262).

These disciplines of the quintessential "docile" human body, regulations of the population and specific regulatory controls resulted in the "biopolitics" of the general population (Foucault, 1986 (1978), p. 262). From these regulatory frameworks rose the development of the various fields of discipline and their political, financial and institutional counterparts we have today such as economics, capitalism, demographics, public health, and diverse institutions: the family, army, schools, police, "individual" versus "public medicine" – and "the administration of collective bodies" (Ibid, pp 261-263).

Women's bodies and the "politics of sex" was encompassed within the objective of "disciplining the body" and "regulating populations." (Ibid, p. 268). The beginnings of the responsabilization of women for not only their own health, but the health of the children they bore, their family members, and the overall health of the social body was "one of the four great lines of attack, along which the politics of sex advanced for two centuries" (Ibid, p. 268). Foucault speaks of the "hysterization of women, which involved a thorough medicalization of their bodies and their sex, was carried out in the name of the responsibility they owed to the



health of their children, the solidity of the family institution, and the safeguarding of society” (Ibid, p. 268). In other words, a healthy body was a clear indicator, taking – “...the individual body as a sign – both as metaphor and as source – of the health or infirmity of the larger social body” (Gallagher, 1986, p. 83).

Foucault’s 1978 lecture on and historical account of his pivotal concept of “Governmentality” – blended the notions of “to govern” (the state) and “mentality” or ways of thinking into one descriptive word and concept. This work delves into and traces how Western society got to a place where, among other things, the social body and the individual bodies within its matrix became subject to normative responsabilization. For Foucault, governmentality bases its existence upon the rational logic whereby the state strives to regulate subjects within its collective population or social body.

Governmentality becomes a vehicle through which norms and normalcy, such as ideation of normal health, normal behavior, and normal appearance are revered as “good things” and aspired to -- as the desired and ultimately state-prescribed way of being in the world. These modes of normalcy, if attained and adhered to, are held up as attributes worthy of praise and reward. On the other hand, those who find themselves inhabiting the realm of the abnormal – those who are viewed as “not normal” (by the state and its governing body) and who do not display “normal health,” “normal behavior” or a “normal appearance” will be focused upon and judged as displaying “bad things” -- presenting a risk to the general population, with its resultant admonishments and punishments. Once a “risky subject” living within a “risky body” emerges into the social body, this situation is rationalized by the state as warranting procedures of greater levels of surveillance and management of these abnormal persons, as embodied subjects of the state, (Foucault, 1991, (1978).

Serlin (2004) explores ‘medical procedures used to rehabilitate or alter the human body’ which had identifiable cultural impacts that are felt in American, and generalized to North American society and culture to this day. He explains how their enlistment “enabled a new alignment of civic goals and national imperatives” (p.1). That is to say, that everything in American society was expected to ‘get back to normal’ following the war. The display of strong, healthy, normal bodies, along with a strong, healthy, advancing nation was expected to be shown by all Americans. Anything less than normal was expected to be kept hidden, kept a secret: “obedient wives, hidden handicapped, the closeted homosexuals ...” -- in other words, the

traditional status quo – the usual “politics of conformity” (p. 2, and back cover). Sameness and blending in was celebrated and rewarded; difference could be reviled, shunned, and punished. Health is categorized as a positive and illness as a negative.

### **Definition of Health, Illness, and the Sick Role: Parsons**

As a founding father of medical sociology, Parsons believed that illness was the negative pair of its positive – health, as well as a “prominent” and “symbolic” source of human incapacity (Parsons, 1978, p. 597). Parsons relied on biologist Mayr’s conception and coinage of the term teleonomy -- defined as “the capacity of an organism” or its tendency “to undertake successful goal-oriented courses of functioning, especially behavior” (Ibid, p. 591) to create his definitions of health and illness. Parson’s expanded upon this linkage of anatomical structure-physiological processes with goal-oriented behavior, eventually undertaking an inclusive extension to action theory vis-à-vis human life and the elements of “personality of the individual, levels of social interaction and cultural symbolization” (Ibid, p. 591).

Parsons came up with what he termed a “tentative” definition of health -- “...the teleonomic capacity that we wish to call health is a capacity to maintain a favorable, self-regulated state, which is a pre-requisite of the effective performance of an indefinitely wide range of functions both within the system and in relation to its environments” (Ibid, p. 591). Maintaining this state involves a capacity to cope with disturbances – both internal or external, including psycho-socio-cultural environments. Therefore, using these perspectives, Parsons put forth that illness could be viewed in the following way: “the illness of an individual should be seen as an impairment of its teleonomic capacity” (Ibid, p. 592). He viewed health and illness as “human phenomena,” which are both “organic and sociocultural” (Ibid, p. 598).

Parsons introduces the notion of the “social role of sickness” and “illness as a social role category” and the “social dynamics” related to people’s lifelong problems of health that are part of human life, from birth to death (Ibid, pp 593-594). His coinage of the term “sick role” taken on by the sick person or patient, to describe his concept -- interacts with its partnered pair, the therapeutic role, taken on by the physician-medical health professional.

His theory conceived the sick role as having four distinct properties that involved institutionally defined rights and responsibilities. The rights of the sick person include: (1.) Exemption from normal social responsibilities; as being ill is not your fault; (2.) Abstention from

occupational-work obligations and family obligations by order of medical authority – via a medical note denoting ‘doctor’s orders’ as a medical injunction; in the case of “chronic” long term illness; sick people and society at large, may have to accept certain “handicaps” regarding the social fulfillment of their social role performance expectations.

The responsibilities of the sick person include: (3.) A commitment to try to recover a state of health – get well in a timely manner or, in chronic or threats of illness, to accept regimens of management that will minimize the health impairment and future risks; (4.) A commitment to cooperate with therapeutic agencies – “physicians” – however, “this cooperation is not definable as a one-way relationship, namely the patient’s simply putting himself under the control of the therapeutic agent. It is a far more complex, reciprocal interaction between these role carriers”. Parsons asserts that the physician’s role functions as a form of “social control” (Ibid, pp 595-596). In his earlier work, Parsons connected illness with the idea of deviant behavior and believed that deviant behavior and illness overlap in some ways -- particularly when the state of illness is “purely mental” or “extending throughout the field of so-called psychosomatic illness” -- but do not occur simultaneously (Ibid, p. 596).

### **Sulik and the She-ro: Frank’s Wounded Warrior Narratives: Restitution, Quest, and Chaos Sulik applies Hochschild’s Feeling Rules to Breast Cancer**

Sulik enlists Arthur Frank’s categorization of the three main types of illness narratives: restitution, quest or chaos to explore how they relate to the dominant breast cancer culture known as “pink ribbon culture” and the heroine of the iconic breast cancer survivor legend, Sulik refers to as the “She-ro.” A She-ro is a “triumphant survivor who fights breast cancer and wins. Those who do not embrace her have no place in pink ribbon culture” (Breast Cancer Consortium, 2019). Further to Parsons’ sick role responsibilities, regardless of their kind of narrative, returning to a state of health – in other words getting well, is expected as an integral part of every sick person’s tale, in this case, all women who have been diagnosed with breast cancer.

Breast cancer survivors’ stories are usually framed as either restitution or quest narratives. Both involve some form of “victory” over the disease. The restitution story distills breast cancer into just three variables, set out in a straightforward, short term trajectory: diagnosis, treatment, and cure – also known as being “cancer-free” (Sulik, 2011, p. 324). The restitution narrative storyline allows for a woman to be temporarily ill for a finite period, but eventual recovery is

presumed with the expectation that she will return to normal as “her old self” – resuming whatever social roles and duties she held before her diagnosis seamlessly. Embedded within this story type is the promotion of surgical procedures of the ilk that will avoid breast disfigurement and then retain, recreate a “feminine body image” or “restore the feminine self” as quickly as possible -- such as lumpectomies and immediate breast reconstruction in the case of mastectomies (Ibid, pp 324-325).

A woman returning to her “normal self” would imply a pre-breast-cancer-diagnosis healthy appearance and a feminine body image of two breasts on her chest – displayed on a body that is now presumed to have been victorious over cancer and is now “cured” or “cancer free” and healthy. She must be healthy, as all heroines appear healthy -- because she is healthy-looking, with no signs of illness visible anywhere on her body – in other words, free of abominations of the body.

However, sometimes a woman diagnosed with breast cancer may find herself turning to tell the quest narrative, whereby her illness has not been a quick three-step process of repairing her temporarily broken body part and restored it to a “good as new” state. As Sulik recounts:

In some cases, women cannot return to their old self. Surgeries may not turn out as intended; treatment may have too many side effects; recurrences happen; or the cancer is too aggressive to be kept at bay in the first place. The restitution narrative does not work, and the quest narrative takes over. (Sulik, 2011, p. 325).

Now her illness has become a full journey, instead of a short trip. The deep suffering and trauma she experiences on her journey begins to cultivate “insight and inspires personal transformation” within her (Ibid, p. 325). As the She-ro, she “fights the disease with style and optimism, learns from her experience, becomes a better person, and shares her wisdom with others” (Cancer Consortium, 2019). She has been transformed into the heroine-triumphant survivor, “either having ‘conquered’ breast cancer” or returned “compassionately humbled” from her sometimes long and arduous battle (Ibid, p. 325).

Sulik identifies that it is this specific discourse and its corresponding visual descriptors that are taken up and utilized in the service of the wider dominant pink ribbon breast cancer culture and indeed, by the overarching cancer industry itself – disseminating these key narrative messages and images via the mass media and in the course of public awareness campaigns. The She-ro survivor’s role now is to offer “inspiration and hope to other women” (Ibid, p. 325).

Setting the standard for survivorship, she has become the public voice for breast cancer survivors, drowning out alternative ways of thinking about and dealing with breast cancer ....Still, diagnosed women continually try to find their own pathways of survivorship and authentic ways to communicate their experiences, even if it means selectively using the tools of the culture itself” (Ibid, p. 326).

The dominant breast cancer culture body image of a She-ro is one of “the heroine” with a two breasted torso denoting a whole and healthy, feminine appearance. A woman whose body has survived intact and still capable of being healthy and displaying a certain expected level of normality and its accompanying health.

Sulik invokes sociologist Hochschild’s classic “Feeling Rules” – all the socially sanctioned, expected, and obligatory feelings we are supposed to or not supposed to have in certain socio-cultural situations and discusses them in direct relation to breast cancer survivorship. In Sulik’s interpretation of Hochschild – “Feeling rules provide a benchmark for gauging how to feel about social roles, relationships, bodies, and illnesses” (Sulik, 2011, p. 228).

The author introduces three feeling rules that she maintains “often occur simultaneously,” “encourage specific behaviors, coping mechanisms, and cultural repertoires” to underpin her analysis of the “impact of social context on women’s experiences of breast cancer and sense of self” (Ibid, p. 230). Feeling Rule 1: OPTIMISM - Survivorship requires a strong sense of optimism in terms of hope, faith, and transcendence. Feeling Rule 2: SELFISHNESS - Survivorship necessitates selfishness, which is constructed in masculine terms as a rational coping strategy or as a confession of gender violations related to women’s nurturance and selflessness. Feeling Rule 3: GUILT – Guilt results from the stigma associated with failing to present oneself adequately as a she-roic survivor, losing bodily integrity, or disrupting gender roles. (Sulik, 2011, p. 230).

If a look of the norm of healthy appearance is to be achieved, a breast cancer survivor is expected not to lose her bodily integrity, nor to think of what is best for herself and her body in ways that could be interpreted as being selfish. These dominant breast cancer culture expectations could apply to a woman making the decision not to reconstruct and to go flat and to live flat – presenting herself in public without prosthetic breasts. Displaying this type of flat-chested body could be interpreted as not having a healthy, female-body, feminine appearance.

Symbolic vestiges of the disease of breast cancer that invaded her body in the form of her visibly amputated breasts, could inspire a backlash of feelings of fear of disease and illness in

others, especially women, as well as feelings of discomfort when people who view her chest are reminded of the harsh realities of breast malignancy. This situation, in turn, could spark feelings of anger and resentment in others who may feel that the living flat woman is not adhering to her responsibility to cover up her mastectomized chest and undertake the emotional labor it takes by putting others' feelings first. She is expected to be engaged in these implied duties, in order to make others feel comfortable, and if she does not, she is made to feel guilty for not doing so. It is her responsibility to help others feel secure that she is healthy, and does not present a threat to society as a risky, unhealthy, abnormal, deviant woman who inhabits the body of a sick person.

Breast cancer survivors are expected to adhere to specific survivorship identity rules and practices as per Sulik, 2011, which almost exclusively entails being cheerful, looking strong, and exhibiting a healthy, two-breasted appearance. What happens when these women actively question or reject these dominant cultural survivor images and seek to invent or adopt alternative ways of being and appearing in private and public life as a breast cancer survivor? What about the women who are choosing to "go flat" and "live flat" – those who are part of and embracing the emerging "flat movement" that is taking place in North America and Europe?

Kaiser, citing Schover, puts forth the reality that most if not all, "other images of breast cancer are largely negative (Schover, 2004) or less available" (2008, p. 82). In other words, some women may view the current dominant cultural ideal of breast cancer survivorship as an "inadequate cultural tool" that does not at all serve their needs, with few accessible alternatives. What then are their options if they turn away from the dominant survivorship persona? Kaiser uses Frank's 2003 work on cancer "survivorship as craft" to explain and extend his original notion of craftwork and its requirement of "practice and the self-conscious construction of one's life" to include the "self-conscious crafting of the (very) meanings of survivorship" (Ibid, p. 82). Kaiser's research found that "women with breast cancer face a conflict between cultural definitions of survivorship and their own ongoing battles with cancer" (Ibid, pp 85-86). For example, a one-breasted or non-breasted woman does not represent the image of the cured survivor who has put all of her cancer battles behind her and swung the pendulum back to a normal, status quo life.

Kaiser's work concludes that many worthwhile and vital changes have transpired regarding the breast cancer experience over the past half-century -- such as a marked decrease in the experiencing of shameful emotions (just because you have become diseased with breast cancer)

and a measurable increase in disease process information and personal and community support. Nevertheless, the sometimes slick construction of a “cure-oriented definition of survivorship,” by the dominant breast cancer culture has left many women searching for representations that acknowledge their fears and the continued presence of cancer in their lives. Because women’s responses to breast cancer are so varied, Kaiser calls for a “better model of life after cancer (that) would acknowledge the variety of responses to the disease and ongoing significance of the disease in women’s lives” (Ibid, p. 86).

### **Charting Their Own Paths**

The myth that medical treatments transform women with breast cancer back into “perfect people” nurtures a dependence on the medical profession and related technologies. ... If each woman with breast cancer understood medicine’s limited ability to control the disease, our reliance on physicians, tests and medical interventions would be enormously reduced. The power of these institutions over us would dwindle accordingly. Without the Rosy Filter, women with breast cancer would gain the right to map our own futures, within the very real constraints imposed by a life-threatening disease.

(Batt, 1994, p. 237).

### **Going Flat and Living Flat Innovated as a Breast Cancer Cultural Tool**

The flat narrative, the go flat movement, its discourses and associated visual and social manifestations of women’s needs are non-traditional, non-dominant ways of coping with breast cancer post-mastectomy. Women who are ‘living flat’ are engaging with the dominant cultural norms of femininity and womanhood while creating more options for themselves. What needs to be considered here is how these norms do not work for some women – as a growing number have difficulties with these norms. At some point in the media interview(s), these media interviewees were asked by an interviewer regarding their breast cancer and motivations for going flat, as well as their living the flat life experiences. In some cases, women had initially undergone breast reconstruction, but due to complications, their implants were removed (called explanting) and following that, they chose not to wear EBPs and to live the flat life publicly.

Some respondents refer to themselves as members of a ‘flat community’ and exhibit an embracing attitude toward their breastless chests. They appear to reject being stigmatized by their flatness and yet embrace and exude a particular pride that comes with refusing to hide the effects of breast cancer surgery and mastectomy; somehow embracing an unmistakable emblem of a woman who has dealt with breast cancer – one who is more than willing and fiercely proud to be

publicly identified by breast cancer but not defined by its tropes. They may wish to emulate flat forerunners Metzger, Lorde or flat advocate actress Kathy Bates.

In this research work, I am expanding on these concepts to include the suggestion that women diagnosed with breast cancer or its genetic risk factors are currently and consciously constructing their lives to include the “flat survivorship” image and its surrounding culture and language. The women in this emerging and growing group do not wish to hide their amputations behind internal or external breast prostheses. They appear in growing numbers to exhibit their “flat pride.” They engage in support and advocacy to help others to live their lives as their bodies are now – uni-breasted or breastless – charting their paths to their unique versions of a “flat identity.”

### **Alternative images: Critique of breast reconstruction and the wearing of EBPs**

Returning once again to the historical higher-profile public figure examples such as Metzger, Matuschka, Lorde, Betteley, Kohlman or Kathy Bates in recent times, “alternative constructions of life after breast cancer co-exist with the dominant image” (Kaiser, 2008, p. 80) of the reconstructed breast or the placement of EBPs. Deena Metzger had her now-famous photograph published as a poster circa the 1980s, showing her triumphant, sun-soaked, post-mastectomy, tree-tattooed, uni-breasted body entitled *The Warrior* with a focussed message in mind. It demonstrates an image that was contrary to the dominant breast cancer constructions, images, and cultures of the day. She and her photographer wanted to “invite the world to look at a one-breasted woman and exult in her health and vitality” (Deena Metzger, Jewish Women’s Archive, 2019).

**RESISTANCE:** Here are examples of women who resist these norms, and by telling their flat narrative(s), makes these norms visible. One narrative of ambivalence is also included.

### **MEDIA INTERVIEWS: Thematic Analysis of Data**

**Paulette’s responses appear in two separate media interviews in this thesis:**

#### **Paulette**

##### **Healthline.com**

##### **“The Power of Mastectomy Scars”**

Medically reviewed by Christina Chun MPH, March 1, 2017.

**Media Interview with Paulette Leaphart: Cathy Cassata**



Paulette is a 50-year-old African American woman from New Orleans, who, after a double mastectomy for breast cancer, and unable to undergo breast reconstruction due to a clotting disorder – “went flat” and lives flat. When Paulette was asked if she would consider getting a mastectomy tattoo, she said no, as she has “learned to embrace her scars.”

**P:**

They tell my story. I would also say ‘no’ today to implants if I could get them. I don’t need breasts to be a woman. Plus, breast cancer is not pretty. Women die every day from this disease. The shock value that seeing a woman with no breasts brings is priceless. Women run to take care of themselves when they see the scars.

Paulette is hyper-aware that her breastless chest and mastectomy scars do not present a body norm of healthy appearance; in fact, its opposite is exhibited. They are a visual indicator of the presence of disease and life-threatening illness; an authentic symbol of illness as deviance and an abomination of the body as deviance (Goffman, [1963] 1986; Gimlin, 2002, 2015; Parsons, 1978). She has decided to make cultural-educational use of her flat chest as a form of therapeutic catalyst in order to motivate women who have viewed her as a “woman with no breasts” and “shock” them into taking “care of themselves.” It can be inferred that Paulette is referring to women being motivated to act out of fear that one day, they could also have a breast cancer diagnosis. What she means by caring for themselves could include actions such as monitoring the health of their breasts by doing breast self-exams or exams conducted by a medical professional, or having a mammogram.

Paulette rejects the feeling rule of guilt for losing her bodily integrity but embraces feeling rule 2 regarding exhibiting selfishness in looking after her own needs over those of others. In this instance, Paulette is not willing to undertake the emotional labor and selflessness it would entail to hide her mastectomy scars and not “shock” people when she reveals her chest with its amputated breasts and resultant scarring. She is not willing to sacrifice her own needs for comfort and healing, which she receives from embracing her scars -- in order to protect others from the harsh realities of breast cancer and its potential threat to women’s lives.

**Elina**

## **1. HerReport.org**

**Finnish Breast Cancer Survivor Elina Halttunen Collaborates with Designers  
Tärähtäneet Ämmät/Nutty Tarts on Monokini 2.0 Swimwear Collection for**

## **Women Who've Had Mastectomies**

<https://www.herreport.org>

June 5, 2014 by Re

### **2. *The Huffington Post***

**Impact: New Swimwear Line Proves You Don't Need Two Breasts To Look Sexy**

Ryan Grenoble: *The Huffington Post*

**HuffPost: Huffingtonpost.ca**

May 29, 2014

### **1. HerReport.org**

Finnish designer Metteri believes Scandinavian countries such as Finland have a greater awareness compared to other nations regarding gender equality. She acknowledges the existence among cultures of a wide range of attitudes toward breast reconstruction surgery – in Finland, the majority of women “more often opt against it.”

**M:**

Our culture, way of thinking and perceiving phenomena are thoroughly commercialized and that makes us very easy targets for visual manipulation and commercial ‘brainwashing.’ We hope that with the social movement raised by the impact of Monokini 2.0, we can change the mentality just a little bit, and raise acceptance toward the diversity of human bodies.

### **2. *The Huffington Post*:**

Monokini 2.0 is a social art project centered on Finnish and American designed swimwear for women who have had a mastectomy. The swimsuits are specifically designed to cover a single remaining breast while leaving the mastectomy scar on the surgical side of the chest exposed. Hence the word monokini versus bikini. Finnish marine biologist and breast cancer survivor Elina Halttunen (age 39 years) spearheaded the project.

**HerReport.org:**

**EH:**

The expectation of having two breasts becomes difficult when you start letting it restrict your life. And unfortunately I suspect this is exactly what happens with many operated women.

Elina received a breast cancer diagnosis ten years ago, had a unilateral mastectomy as part of her treatment and decided against reconstructive surgery. She became a uni-breasted woman. This transformative experience sparked the concept for this project.

After my operation, I remember I thought that I had become breast-fixated. I felt I saw breasts everywhere, but after a while I realized that this pretty much is the case. Our whole culture is breast-fixated; I had just become a bit more fine-tuned to the fact by becoming an outlier.

Losing my left breast was not such a big deal for me. After all it had cancer, I wanted to get rid of it. I just did not want to undergo a new operation, especially not a procedure that would have required several operations with a suite of possible complications. I did not see the point, especially as I would not have regained the feeling in the reconstructed breast. I saw it as a cosmetic operation that I did not need; I got used to how I looked as one-breasted, and my scar became part of me – a healthy reminder of my mortality and therefore my priorities in life.

***The Huffington Post:***

**EH:**

I do not want to hide. I do not want to stop swimming. I do not want to undergo extensive plastic surgery operations, and I do not want to be forced to use the uncomfortable prosthesis on the beach. I want to feel as free and active as I did before my cancer, and I am pretty sure that there are others out there like me.

Elina wants to continue an active, healthy lifestyle as she did before her breast cancer diagnosis and unilateral mastectomy. She wants to wear swimwear that does not impede her wish to be “free and active” – which denotes her desire to be healthy and to return her body to a state of health. By wearing a “monokini” swimsuit designed especially for her single-breastedness, she communicates that there is no need to cover more than her remaining breast and leave the amputated side of her breast minimally covered, or not covered at all, since it is breast-free and is now just skin and scar tissue that remain in its place. Is her body healthy-looking, and does it conform to the body norm of a healthy appearance?

Under the body norm of a healthy appearance, it would not be categorized as having a healthy appearance due to its abomination of the body in its uni-breasted deviance. The underlying message of why she is one-breasted resulting in an asymmetrical chest refers back to breast cancer disease; the reason for her mastectomy is culturally unmistakable as a symbol of a well-known illness that is responsible for such a surgery. For reasons very similar but not entirely the same as Paulette’s, Elina does not feel guilty for losing her body integrity; nor does she feel responsible to engage in emotional labor to protect others at the beach from feeling shock, horror, fear, or any other unsettling or uncomfortable emotion that may be elicited when other bathers view her uni-breasted body with an exposed mastectomy site. However, to herself, Elina is

undertaking what Sulik referred to as “women (who) continually try to find their own pathways of survivorship and authentic ways to communicate their experiences, even if it means selectively using the tools of the culture itself” (2011, p. 326). Elina hired fashion designers to design a “monokini” that allows her to engage in a healthy sport and look and feel “attractive and sexy” entirely on her terms.

As per Parsons’ sick role rules, onlookers may wonder if she is “still sick” or if she has made enough of an effort to become well. Alternatively, they may wonder why she has not adhered to her responsibility of getting reconstructed and “normalizing” her appearance for the emotional comfort of others if that was her doctor’s advice? In the dominant breast cancer she-ro culture, having a normal, healthy appearance is part of looking-well, recovered, and “back to her old self.” What Elina has decided is that she is going to follow feeling rule number two and that her survivorship involves selfishness, in that she feels good and is looking after her health and healthy appearance by participating in swimming exercise, and this is the coping strategy that she has chosen and feels positive about for herself. The idea that her appearance may not come across as healthy or “back to normal” to others does not concern her, vis-à-vis her unique survivorship needs.

**Kathy  
Celebitchy.com  
July 12, 2017**

**“Kathy Bates had a double mastectomy five years ago, hasn’t had reconstruction.”  
*Cancer, Illness, Kathy Bates* By: Celebitchy  
From WebMD media interview via *Daily Mail***

Hollywood actress Kathy Bates, 69, had a double mastectomy for breast cancer in 2012.

Today, if Bates doesn’t have to wear her breast prostheses for a role, she doesn’t put them on.

KB:

I’ve joined the ranks of women who are going flat, as they say (laughing). I don’t have breasts – so why do I have to pretend like I do? That stuff isn’t important. I’m just grateful to have been born at a time when the research made it possible for me to survive. I feel so incredibly lucky to be alive.

Kathy underscores the disease process and her illness, having the potential to be a life-threatening one. She appears to equate a healthy body appearance to being fortunate to be alive, which she credits to advances in breast cancer research; although dominant Western culture, especially that of Hollywood Americana, may not perceive her body as having a healthy appearance. She has

lost her body integrity but rejects everyday use of external prostheses unless she is contracted to do so for her work as an actress. Her lived experience is that of a woman publicly living flat. Her body is breastless and therefore she has an abomination of the body that is considered deviant by the dominant society and hegemonic breast cancer culture.

Bates is a relatively well-known American film actress and because of this she has a certain amount of cultural influence within the North American breast cancer cultural milieu. Some may view her as a ‘flat role model’ and want to follow her example, as they see her wanting to prioritize authenticity over normative and a perceived healthy appearance. She also makes it clear that she feels being alive trumps having false breasts displayed on her chest. She is forging her own new identity in her newly flat-chested body. These concepts parallel Sulik’s belief that despite the dominant she-ro image, women will still be able to “find their own pathways of survivorship and authentic ways to communicate their experiences,” coping strategies and being a breast cancer survivor in their own unique ways (Sulik, 2011, p. 326).

## **Robin**

### **Narrative of Ambivalence**

**February 23, 2017**

**FORCE: Facing Our Risk of Cancer Empowered**

**[www.facingourrisk.org](http://www.facingourrisk.org)**

**“Post-Reconstruction Thoughts of ‘Going Flat’”**

Robin Karlin is a white American female who considers herself a feminist, who tested positive for a BRCA1 breast cancer mutation. She had a bilateral prophylactic mastectomy and undertook extensive research regarding her options of having breast reconstruction or going flat. Even though she found fresh messages in her research that rang true for her – ones that eschewed the traditional androcentric standard of beauty, like the one from breast cancer survivor and flat advocate Melanie Testa’s blog that said: “For me, beauty ideals and expectations related to the female body are a form of tyranny. I resent that in the face of a lethal disease, the conversation turns to hair and wigs, reconstruction, and ‘Look Good, Feel Good’ programs” (Testa quoted by Karlin, 2017). However, in the end, Robin said:

Despite all this I just couldn’t see myself living without breasts.

I knew that I would lose sensation in my breasts. I somehow thought that if they looked “normal” they would help me feel sexy. I proceeded down the normative path despite some embarrassment about what I saw as an abandonment of feminist principles. I had a serious complication after my reconstruction, and my outcome after four surgeries is far

from beautiful. I have learned to accept my body as it is and I make myself feel beautiful by nurturing my health, by exercising, and by dressing in ways that express my creativity. I still miss my former sensate breasts and have found my “foobs” to be pretty useless during sex. What was I thinking, I wonder now?

Robin’s lived experience with wanting to look “normal” after a preventive double mastectomy and her inability to envision herself as a breastless woman, motivated her to have reconstruction. Following four surgeries, a “serious” complication, and a “far from beautiful” final outcome, she is now learning to accept her new normal body as it is. Robin responded to her risk of developing breast cancer from a BRCA1 gene mutation by having both her breasts amputated. She hoped to normalize her appearance by having her breasts reconstructed; her ideation included thinking that internal prosthetic breasts would “help” her feel “sexy.” One crucial question could be – Did Robin feel “sexy” before the mastectomies? Was feeling “sexy” part of her having a normal and healthy appearance? Did she fit into the known research regarding the majority of women who have body-image issues compared to men, and breast cancer surgery may complicate them further (Bordo, 1989; Gimlin, 2002; Mahalik et al., 2005).

In her quest for a normal-looking appearance, she ended up having to accept a body that is “far from beautiful.” Now she wants to nurture her health and by extension a healthy appearance, by “exercising and ... dressing in ways that express (her) creativity.” She laments the loss of her natural breasts that had all their nerves attached and thus normal sensation. She describes her “fake boobs” as “pretty useless during sex.” This comment can be interpreted as Robin realizing that her reconstructed breasts are failing to offer her the kind of “sexy” feeling that she was anticipating, leaving her disappointed with her reconstructive outcome. As a self-described feminist, through her narrative of ambivalence, she is still trying to figure out why she felt so strongly about having her breasts reconstructed and why she could not envision herself without breast mounds on her chest.

## **Embracing the flat identity**

**Marie-Claude**

***La Presse* Édition du 13 janvier 2019,  
Section PAUSE CAFÉ. Écran 2  
A Dossier by Marie Allard  
English Version by: Google Translate  
“The Right to be Flat”**

Québécoise Marie-Claude (age 31 years) – founder of the community Facebook flat choice information page *Tout Aussi Femme* (Still A Woman) and her partner Marcella, live in Montreal (Poisson, *Journal Métro*, 2018). Diagnosed with breast cancer in 2016, which progressed to stage 4 in 2017 (Ibid, 2018), Marie-Claude had a double mastectomy, although just one breast had the malignancy. She was always sure about not wanting reconstruction, and articulates several reasons motivating her decision – as an active outdoor person, she wanted a short recovery period (healing from the mastectomy itself), and to subject herself to as few medical interventions as possible:

It does not interest me to get breasts that are not mine. I do not want breast prostheses. Having a foreign body in me, I'm not ready for that. (I was always clear with my doctor about my decision) but I *almost* woke up after the operation with (skin) expanders. The oncologist had written on the operation request – 'laying expander, breast reconstruction'. I asked her why she did that, and her response was '*You're so young*'. I realized that there is a certain paternalism. Our society urges women to be rebuilt, reproducing the hetero-normative discourse that believes motherhood, sexuality and femininity necessarily pass through the breasts.

Having and displaying a mono-breast is even more invisible in society. I wanted symmetry, I did not have a role model (of a single-breasted woman). Today I would make another choice, I would remove one. But I have no regrets. In recent months the (flat) movement is organized, especially in English Canada and the United States. We are forming a big, big flat community. (As of June 2019, the search terms 'flat' or 'going flat' or 'flat chest' show no results on the Quebec Breast Cancer Foundation web page).

Although Marie-Claude believes her decision -- a definitive “no” to having breast reconstruction was communicated very clearly to her doctor – and in her analysis of what had ‘almost’ taken place, she deduces that a form of ‘medical-milieu’ paternalism had occurred. Employing Dworkin’s original 1972 theoretical concept of paternalism to mean “the interference with a person’s liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced.” In order to meet Dworkin’s definition of paternalism, the criteria should include an action that (1) limits a subject’s freedom, (2) is performed without the subject’s consent, and (3) is performed with a beneficial intent (Britannica.com, 2019).

It can be presumed that Marie-Claude had the ‘error’ written on the surgical consent form corrected, as she does not appear to have, nor mention tissue expanders being in place at the end of her bilateral mastectomy. She did question her surgeon as to why such an order was written on

her surgery procedure form. The reasoning her doctor gave for ordering the placement of expanders in preparation for eventual breast reconstruction was because Marie-Claude was “so young” – she was in her late twenties at that time. Her lived experience satisfies Dworkin’s paternalism criteria. Marie-Claude’s liberty of action, her freedom to choose to be flat and not to have her breasts reconstructed was interfered with. The tissue expander procedure would have taken place without Marie-Claude’s consent, but the doctor believed that she would be performing this action of surgery with a beneficial intent, justified by Marie-Claude’s age, and the presumption that young women would always want to have their breasts replaced with implanted ones. Marie-Claude is refusing breast reconstruction, and along with that, she is rejecting the hetero-normative social identity of a young woman who is socially obligated in some way, shape or form, to display some type of permanent breast mound(s) on her chest. She now identifies herself as a young woman who has used her sense of agency to ‘go flat,’ to ‘live flat’ and to identify as a Québécoise who is a member of a broader flat movement community that is growing across North America.

**Joanna**

**CBC Radio**

**Posted: January 19, 2019**

***White Coat, Black Art***

**The Doc Project – Radio Documentary-Podcast**

**Alexandra Zabjek – Producer-Journalist**

**Edmonton, Alberta**

**“After breast cancer and failed reconstruction, this mom found beauty by going flat”**

Joanna (age 40 years) was a 32-year-old Toronto Ph.D. student, wife, and mother to a young son when she received her breast cancer diagnosis. She was informed that her treatment protocol would include a double mastectomy, chemotherapy, radiation and the insertion of skin stretching expanders, as the first phase of immediate breast reconstruction -- would be done at the same time as her mastectomy surgery. A nearly instantaneous post-operative complication of acute infection quickly developed. Although Joanna was very ill and weak from the infection, her plastic surgeon insisted she should continue to the second phase of her breast reconstruction, which is to insert the breast implants under each expanded skin cavity during another surgery.

In retrospect, she realizes that due to her general vulnerability of being in a weakened physical and emotional state, she was “unable to stand up to her plastic surgeon” and assertively say ‘no’ to continuing with having the implants inserted into her chest (Zabjek, 2019). For six



months following the implant insertions, Joanna suffered from more infections as well as other complications. Finally, when her health crisis peaked, her implants were both removed (called explanting) due to widespread, chronic infections. Joanna had finally had enough, and “wanted nothing to do with implants again” (Zabjek, 2019) and decided to “go flat.” “Joanna is part of a growing “flat positive” movement, which includes groups like *Flat & Fabulous* and *Flat Closure Now*. On its website, *Flat Closure Now* says they advocate to ensure ‘breast cancer patients and providers understand that ‘going flat’ is a valid, beautiful and healthy surgical option after mastectomy” (Zabjek, 2019). After an adjustment period, she “eventually (went on) to celebrate and accept her chest, joining (this) “flat positive” movement that advocates for women who don’t want to undergo reconstruction after a mastectomy” (Zabjek, 2019).

Looking back on her experience, Joanna now realizes -- but also wonders why it is that she “felt pushed” into agreeing to breast reconstruction and “wonders if her young age affected how they approached her case” and that her “implant ordeal was (the) worst part of her cancer journey” (Ibid, 2019). Inspired by a photograph she saw on an online flat community, of a “woman standing in the ocean, with a huge octopus tattooed across her flat chest and over her shoulder” -- now Joanna has matching swallows tattooed on each side of her flat chest, which are traditional sailor tattoos – symbolic of “the safe return from a journey” (Ibid, 2019). Joanna felt inspired (to get her chest tattoos) by the image of this tattooed, breastless, flat-chested woman – “She just looks so happy and sort of proudly displaying her scarred and flat body.”

Everyone just kept telling me that I would have a psychological breakdown if I woke up from surgery and didn’t have breasts. I certainly had a lot of reservations about it, but all of the medical teams told me repeatedly how hard it would be for me. They would always tell me that you’ll have chemo and radiation and surgery and reconstructive surgery as well. Some of my stitches opened right up, and there was just a gross ooze coming right out of them all the time. At the end of the worst part of my infection, I was having pus coming right out of my skin all over my breasts.

(“The experience of showing her scarred chest to a stranger was both painful and liberating to Joanna” (Ibid, 2019) And also the physical pain of the tattooing process).

To have that experience of pain that I chose rather than having that medically forced on me was really empowering. And then to create something that I think is beautiful over top of a space that I just felt so ugly and fraught with emotion – it was empowering to me. And now I’m good with that. I feel I reclaimed that space from medical authority. It’s my body again. It’s part of me.

Joanna went flat due to what is termed “failed” breast reconstruction surgery. In her case, acute, then recurrent, turning into chronic infections – initially of her tissue expanders and then the implants themselves. Six months of this situation acted as a strong motivator for Joanna to reject her breast reconstruction altogether and have them permanently removed from her body. Like Marie-Claude, she also experienced a form of medical paternalism. From the beginning, all her medical treatments, including her reconstruction surgery, were unilaterally prescribed to her, instead of being discussed as part of a shared decision-making process. As part of her informed consent protocol, she was not given the full array of options available regarding post-mastectomy surgical outcomes, such as going flat and having a specific “flat closure” surgery that can be categorized as a specialized type of post-mastectomy plastic surgery.

Although knowledge of these options may not have been as readily available at the time of her surgery in 2011, presentation of the option to ‘do nothing’ and not to reconstruct, was not presented in a non-biased manner. Joanna was not asked about her values, priorities, and personal socio-cultural feelings toward her breasts and losing them. Her medical team appeared to assume, especially because she was a young woman, that she would automatically opt to have her breasts reconstructed. Despite her weakened and ill state from medical complications, her plastic surgeon’s insistence that she proceed with the implant surgery could be interpreted as inappropriate or even unethical, given Joanna’s overall medical condition. In turning to flat positive resources online, Joanna was able to create another post-mastectomy option for herself – one that felt right for her and left her feeling empowered, liberated, and beautiful. Ultimately, Joanna expresses that she was able to “reclaim” her body from “medical authority” – a significant component of her reclamation, was the use of post-mastectomy chest tattoos.

According to the “Going Flat” resources on the “flat” education and advocacy website *Flat Closure Now*, there are multiple reasons and circumstances that result in a woman’s decision to have her breast implants removed. As per the *American Society of Plastic Surgeons*, more than 19,000 breast cancer patients decided to have their breast implants explanted in 2017 (Plasticsurgery.org, 2019). These reasons may include one or more of the following: chronic infection or inflammation around the implants, implant rupture or silicone leakage, capsular contracture – hardening of the scar tissue surrounding the implant, exhaustion with multiple corrective or exchange surgeries (required every 10-15 years), general dissatisfaction with the implants’ appearance, persistent feeling that the implants misalign with body image, physical

discomfort – tightness, pain, temperature differential, numbness, simply not wanting to live with implants anymore, concern about BIA-ALCL – a cancer linked to breast implants by the FDA and WHO and various other medical complications ([www.flatclosuresnow.org](http://www.flatclosuresnow.org), 2019; Plastic Surgery.org, 2019).

United States plastic and reconstructive surgeon, professor and health services researcher Dr. Clara Nan-hi Lee and her research team asked – “How informed is the decision (that breast cancer patients make) about breast reconstruction after mastectomy” (Lee et al., 2016, p. 1103)? Prior to their planned mastectomies, 126 breast cancer patients completed a survey designed to assess their knowledge about breast reconstruction and their involvement in decision-making.

The results showed an overall knowledge score of almost 59/100, with knowledge regarding complications risk coming in at just 14%. The majority of women at between 90-92% reported they had discussed reconstruction and been asked about their preference with their providers. On the topic of advantages versus disadvantages of undergoing breast reconstruction, close to 58% reported discussing the advantages, as opposed to close to only 28% reporting that the disadvantages of the procedure had been discussed with them.

Lee et al. 's research concludes that the participants in this study “had major deficits in knowledge about the procedure.” Women’s knowledge regarding risk of complications was “particularly low.” Additionally, it appeared that their health care providers had spent more time discussing the “advantages of reconstruction more than its disadvantages.” (Ibid, 2016).

In 2018 plastic surgeons Dr. Offodile II and Dr. Lee published an analysis of the “Future Directions for Breast Reconstruction on the 20th Anniversary of the Women’s Health and Cancer Rights Act” (Offodile II & Lee, 2018). Their piece describes the past 20 years of medical industry “effort” that has gone into “enhancing access to breast reconstruction surgery” in the United States – leaving a legacy of enduring “concerns about safety, efficacy, and overuse” (Ibid, pp 605-606).

These authors put forth the following key, current evidence-based overarching issues as main points, as well as suggestions for long term directions: the effectiveness of breast reconstruction has not been fully established, and its ability to produce outcomes important to patients remains unclear; the safety of immediate breast reconstruction remains unclear -- along with addressing access to reconstruction, surgeons need to improve the safety of breast reconstruction; elective breast reconstruction’s complication rates exceed those of other major elective procedures, and

are comparable to those of open-heart surgery; the likelihood of surgeons discussing the positive advantages of reconstruction is disproportionate to them discussing its negative disadvantages results in a definite lack of patient breast reconstruction knowledge -- leading to a high patient underestimation of major complication risks; surgeons are not trained in how to elicit patient preferences relative to reconstruction – without explicitly doing this, a surgeon is unlikely to know what the patient values; it is crucial for surgeons to ask each patient what is most important to her without assuming that all or even most women prefer breast reconstruction.

According to Offodile II and Lee, future research priorities need to focus on the reduction of morbidity – along with the risk of short and long term complications and changes in physical functioning; another priority should be given to developing and implementing previously proven shared decision-making interventions, that could include patient decision aids and decision coaching – as they greatly assist in improving the quality of decisions; policy mechanisms at federal and state levels would promote positive clinician behavior change – as well as enshrining these changes legislatively – citing the Washington State 2007 example that acknowledged shared decision making as a vital component of the informed consent process (Offodile II & Lee, 2018, pp 605-606).

**Gemma**

***DailyMail.com UK***

**<https://www.dailymail.co.uk>**

**Vanessa Chalmers Health Reporter for MailOnline**

**Published: 3 December 2018**

**“Mother-of-three embraces her mastectomy scars and flat chest by posing topless after beating cancer three times”**

Gemma (age 49 years) lives in London, England with her husband and three children. Gemma’s story explains how she eventually came to have a double mastectomy. Although her initial breast cancer diagnosis was six years ago, her cancer illness, treatment trajectory, and eventual removal of both her breasts did not follow a stereotyped linear A, B then C paradigm. Initially, cancer was identified in just one of her breasts, and her treatment plan involved three lumpectomies then radiation. After two years, Gemma had a same-breast cancer recurrence, this time with a regional spread of cancer cells to her underarm lymph nodes. This situation necessitated a mastectomy. Once again, two years following that, she sensed something was “not

right” about her remaining breast – “I had an inkling something wasn’t right. When they removed the breast, they found that it too had cancer in it.”

Since 2017 she has been considered cancer-free. She described her doctors’ offerings of a breast reconstruction procedure as ‘persistent’ – however, she kept repeating to them that this was something she did not want to have done. In 2018 she participated in a topless photo shoot that was published in the *Daily Mail UK* online newspaper. She states that this photo project had multiple goals: “to show the ‘real’ side of surviving breast cancer to other women as well as to empower women to say ‘no’ to surgical procedures they may feel ‘bullied’ into having and instead feel lovable regardless of their appearance.”

After I decided to have a mastectomy, I really felt that I had let my surgeons down, that I was a bit of a disappointment to them. They obviously know what they can make you look like with reconstruction, but I felt quite strongly that the decision should be mine. I was really encouraged by the hospital to have reconstruction, but I didn’t want to. I actually feel normal. I rarely think about it, other than if I’m in a situation where I have to get dressed/undressed with other people, like at the gym. I know I’m fine with how I look – I’m just aware that others might not be.

I’m very lucky that my husband is just super happy I’m still on the planet and isn’t bothered by how I look. I decided to do the photo shoot as it’s important to me that other women in my situation feel empowered to make their own decisions and that you are still the same person inside, you can still love and be loved. Make your own decisions about your health and your body and don’t be bullied into an immediate decision. Feel happy in your own skin. I don’t really think of deliberately wanting to be inspirational, I just want others to know that life can go on as normal even if you don’t quite look the same.

Are women like Gemma creating another future option for breast cancer culture -- whereby they are creating their own choices and ideology for themselves – new tools to retool or recreate their lives, new tools that better serve their needs and ways of coping with their post-mastectomy bodies? Through acts of self-determination, they are defining flatness as a legitimate choice. Gemma is demonstrating her resistance to the dominant norms of the expectation from her medical professionals that she will have her breasts reconstructed. She has expressed her thoughts and feelings to the contrary – that this particular norm does not work for her. It appears that her medical team did not offer her a flat-positive option – and that they were focussed on giving her one single choice – breast reconstruction. Gemma expresses clearly that she already feels “normal” and does not need reconstruction to make that feeling happen for her.

How she has come to feel that she has “let down” her surgeons, and become “a disappointment” to her medical team by merely choosing not to reconstruct, would warrant more

probing as to how, when and why these uneasy and perhaps painful or distressing emotions started, had this been a live one-on-one interview. From her resistance being made public in the form of formal photographs being published in an online newspaper, she is ultimately providing another, currently growing example of women who resist – by Gemma telling and displaying her going flat narrative, she is making the dominant norms more visible. However, although these dominant norms of breast reconstruction expectations may not be working for some women such as Gemma, they are not universally a problem for all women, as significant numbers of women continue to undergo breast reconstruction procedures.

How women who have their breasts reconstructed post-mastectomy come to arrive at a perceived ‘decision’ is something that appears to require further study and research (Offodile II & Lee, 2018). In addition to this, more discourse analysis is needed on what happens when women with breast cancer resist a traditional and conventional reconstruction treatment option that mostly originates within and is communicated from the medical professional domain – that is, from their general practitioners, oncologists and plastic surgeons (Crompvoets, 2006, 2012).

The motivations for choosing to go flat vary widely, and although Gemma does not express any specific reason or motivation for saying no to reconstruction in this media interview, other than saying that she “didn’t want to,” the fact that she already felt “normal” (without breasts), she felt “strongly” that any medical decisions regarding her body should come exclusively from her, and that generally speaking she has chosen self-acceptance of her new-normal breast-free body -- encouraging herself and others to “Feel happy in your own skin.” Even though she does not appear to be receiving the “cultural authorization” that Couser spoke of – when she states “I know I’m fine with how I look – I’m just aware that others might not be.” – moreover, she feels her life has gone on “as normal” despite not “looking quite the same.” In effect, Gemma has utilized this tool from her toolbox and “normalized” her option and decision to go flat and to live a flat positive life. According to the “Going Flat” resources on the “flat” education and advocacy organization website *Flat Closure Now*, most women are motivated not to have reconstruction “by a desire to minimize their surgeries, risk of complications, and length of recovery.”

Ultimately, it appears that Gemma has demonstrated her ability to reject a sense of stigma and spoiled identity itself (Goffman, 1963, 1986). She also corroborates Major & O’Brien, regarding stigma, when she says she feels “normal,” and happy in her own skin; she is “fine” with how she looks, however, when in a social context, she becomes aware that “others might not be” -- “fine”

with her appearance as a flat-chested woman. The social context example she uses is when changing at the gym. As per Major & O'Brien, "Importantly, stigma is relationship-and-context specific; it does not reside in the person but in a social context" (2005, p. 395).

**Sue**

***Stand Up to Cancer UK***

**Video: "Having a Mastectomy Tattoo" – Sue's Story//One Minute Stories (2018)**

**YouTube *StanduptocancerUK***

<https://youtu.be/XAm2ZryMwX8>

In 2008, Sue who is a mature Caucasian woman (no age stated) living in the United Kingdom, was diagnosed with a "very aggressive" form of breast cancer. She underwent bilateral radical mastectomies as part of her treatment.

Having a radical mastectomy is really invasive – obviously, and for me to have a woman's breast cut away, removes a feeling of femininity – emotionally as well as physically. I knew that I didn't want to wear prostheses. I didn't want to deny what cancer – how it had had an impact on my life. That was the first point of actually *reclaiming my body*, and I thought "How can I do it?" And I decided on a tattoo. Every morning when I get up, it still puts a smile on my face! (Laughs). I'm enjoying my tattoo. I'm living life to the full, and it means a great deal to me.

For Sue, having her breasts amputated gave her an emotional and physical experience of taking away her "feeling of femininity." She is definite in her wishes not to wear prostheses. She does not mention anything about breast reconstruction, nor state any reasons for not undergoing it. However, in view of her having had *radical* mastectomies for a particularly aggressive type of breast cancer, there may have been other medical case factors at play that are not discussed in Sue's media interview.

Motivated by a desire not to deny how cancer had impacted her life, Sue became aware that she wanted to "reclaim" her body; reclaim it from what she perceives cancer had taken away from it, which includes her feelings of femininity. However, she did not know how to go about this reclaiming process; what actions she should take to make that reclamation happen. She finally decided on a full chest tattoo, and now finds it has deep meaning for her and contributes significantly to her *joie de vie*. Similar to Joanna's situation, Sue's post-mastectomy tattoos prove to be an invaluable, innovative breast cancer coping tool, one that speaks once again to Swidler's "cultured capacities" – choosing new tools to cope with a new, post-mastectomy body (Swidler, 1986).



*Figure 2: Sue YouTube StanduptocancerUK:  
“Having a Mastectomy Tattoo” – Sue’s Story//  
One Minute Stories (2018) Video screen shot (still).*

## **Results, Discussion and Conclusion**

This qualitative research has shown that breast reconstruction and the wearing of prosthetic breasts are valuable coping mechanisms for some women post-mastectomy. While these cultural tools from the dominant breast cancer culture discourse are embraced by many mastectomized women, they are underpinned by dominant body norms. The dominant body norms used in the analysis of the media interviewees’ data are those of body part replacement, having a feminine appearance, and having a healthy appearance. A growing number of women are starting to reject these options for newer innovations that are created by and for themselves. This breast cancer cultural phenomenon has been ‘named’ in popular and breast cancer culture as ‘going flat’ and ‘living flat.’

Results of this study showed these women’s motivations for resisting reconstruction and the wearing of prosthetic breasts after mastectomy, otherwise known as ‘going flat’ and ‘living flat,’ varied widely. To summarize, they include – Regarding reconstruction: implants removed (explanted) on a permanent basis due to recurrent infections; adverse body reactions that made them feel unwell; simply not wanting to live with implants anymore; was not an option for medical-surgical reasons; physically active lifestyle initiated a desire to have a short surgical recovery period from mastectomy alone; reluctance to undergo multiple reconstruction surgeries



with ensuing risk of complications; not wanting a reconstructed breast void of sensation; not wanting a “foreign body” placed inside the body; notions of authenticity along with not wanting to “pretend” to have breasts; not wanting to be “bullied” into having reconstruction versus wanting to have all medical decisions regarding the body to be theirs alone; simply “not wanting” to have reconstruction; already feeling “normal” after mastectomy surgery so did not feel need to have reconstruction nor wear EBP’s to normalize themselves. Some women were motivated by online images of women with tattooed chests who had ‘gone flat’ and were living an uncompromising ‘flat life.’

Regarding motivations for rejecting the wearing of EBP’s – were as follows: not wanting anything hiding the scars as felt they had “embraced” their scars and they were now a part of them; had had chest tattoos and felt they had reclaimed their bodies for themselves – via employment of tattoos they did not need nor want EBP’s hiding the beauty of their tattoos; not wanting to be “forced” to use “uncomfortable” EBP’s and by extension and implication, not seeing EBP’s as compatible with a physically active lifestyle; just not wanting to wear EBP’s.

Of the ten ‘living flat’ media interviewees featured in this research, four out of ten women had initially received breast reconstruction with implants – Marianne, Thedra, Samantha and Joanna. For various reasons, all four had their implants explanted (removed) permanently; they also all chose not to wear EBP’s as well, and subsequently started a life of ‘living flat.’ Influencing factors for explanting included: two out of four had recurrent infections (Marianne and Joanna); Marianne is adamant that had it not been for this complication factor, she would have kept her implants when she states “I didn’t choose flat, flat chose me.” One out of four decided to explant after having implants for eight years but verbalized no motivating factors in her media interview (Samantha); sometimes plastic surgeons categorize this as “simply not wanting to live with implants anymore” (Flatclosurenow.org, 2019). One out of four had her implants removed because she felt her body reacted adversely to the implants by giving her signals of rejecting them (Thedra). According to the *American Society of Plastic Surgeons*, in 2017, over 19,000 breast cancer patients had their breast implants removed (Plasticsurgery.org, 2019). None of these four women verbalized any identifiable motivating factors for not wearing external breast prostheses.

Six out of ten media interviewees did not undergo reconstruction from the time of their initial mastectomy: Paulette, Elina, Kathy, Marie-Claude, Gemma, and Sue; in other words, they ‘went

flat’ from the beginning. Five out of six women had double mastectomies, and one had a single breast amputated (Elina). For two of the six media interviewees, reconstructive surgery was not an option for medical-surgical reasons (Paulette and Sue). An initial decisive influencing factor for Paulette was having a pre-existing medical-surgical risk factor – a clotting issue was stated in her case. Nevertheless, Paulette later states that even if she could have implant surgery, she would say ‘no’ to it, as she does not want to hide her scars – they are something she now “embraces” and does not need breasts to be a woman. For Sue, it could be surmised that due to her aggressive form of breast cancer and the necessity for her to have a bilateral radical mastectomy, these conditions could have made reconstructive surgery a challenging and perhaps not a viable surgical option -- although this is not stated in her media interview.

Motivations for not choosing reconstruction for the remaining four out of six were as follows: Elina and Marie-Claude’s were multi-factorial and mainly motivated by their physically active lifestyle. They wanted a short surgical recovery from mastectomy surgery alone and did not want to undergo the multiple new surgeries required for breast reconstruction and the ensuing risk of complications. Elina did not see the point of having a cosmetic option that would yield an artificial breast that has no sensation. Marie-Claude had always been sure about not wanting reconstruction as did not want a “foreign body” in her. As for the remaining two of these four – Kathy and Gemma: Kathy explains her motivations for being ‘flat’ as coming from an element of the notion of authenticity. She communicates the fact that she does not have breasts now, and does not wish to “pretend” to have them; neither does she feel that making a pretense of having them – “that stuff” – is “not important” to her. In Gemma’s case, her motivations for rejecting reconstruction seem to stem from being averse to being “bullied” into having them. She feels “strongly” that any medical decision regarding her body should be hers and hers alone and states that she “did not want to” undergo reconstructive surgery.

None of these ten media interviewees said they wore EBP’s. Six out of ten women did not mention anything about EBP’s nor any motivators for their choice to reject wearing them. Marianne, Thedra, Samantha, Marie-Claude, Joanna, and Gemma all appear to live a completely ‘flat’ life, void of EBP’s. In Marie-Claude’s case, it could be inferred that given the physical and practical constraints that EBP’s can impose on one’s body when engaging in an active outdoor lifestyle, they would most likely be eliminated from her ‘tool kit.’ It can also be inferred that Joanna’s chest tattoo has contributed so heavily to the reclamation of her chest space and body

from “medical authority” that she does not need nor want anything else ‘medical’ covering over the “beautiful” area she has had created for herself. As for Gemma, it could be deduced from her media interview data that she already feels “normal” being flat, so she would not feel the need, nor see any personal or social benefit from wearing EBP’s.

Four of the ten women did mention or allude to the wearing of EBP’s as something they felt was not wanted nor necessary in their lives: Paulette, Elina, Kathy, and Sue. Paulette does not want a mastectomy tattoo and, by extension and inference – EBP’s, as she does not want anything hiding her scars – she has learned to “embrace” them -- as they are now part of her that “tell” her “story.” Elina does not want to “hide” in any way shape or form. Like Paulette, her unilateral mastectomy scar also became part of her. Similar to Marie-Claude, she is also physically active, loves swimming, and did not want to be “forced to use the uncomfortable prosthesis on the beach.” Kathy’s media interview data reveals she is adamant that now she is breastless; she does not feel the need to “pretend” she has breasts. She uses EBP’s only when she is contracted to do so, agreeing to it in order to make her living as a professional actress – otherwise ‘living flat’ on an everyday basis. Sue has a full chest tattoo, which has deep meaning for her. She states explicitly that she “did not want to wear prostheses” but does not give any particular motivations for rejecting their usage. Similar to Joanna, it could be surmised that since Sue has stated that she wanted to “reclaim her body” and did so by getting her full chest tattoo. Sue wakes up every morning, “enjoying” her tattoo – it puts a “smile” on her face. Therefore, Sue appears to have no desire nor need to wear external breast prostheses, as her full chest tattoo fulfills her post-mastectomy coping and feminine body image needs.

All ten women interviewed appear to have enabled and empowered themselves to reject the concept of stigma and spoiled identity. They seem to resist fulfilling the social role of a person marked with an “abomination of the body,” a woman with a “spoiled identity,” one with “a form of deviance” -- who is then stigmatized by dominant breast cancer culture and larger normative society as a whole (Goffman, 1963, 1986; Gimlin, 2015). All ten media interviewees engaged in ‘flat pride’ behaviours such as being interviewed, photographed and filmed for dissemination in the public domain, and some referred to feelings of “pride” and “being beautiful” regarding their or others’ ‘flatness.’ None of the media interviewees’ data appeared to indicate they were engaged in the emotional labor of concealment so others would feel more comfortable or less distressed by their mastectomized appearance. They all seem to be following Sulik’s

interpretation of Hochschild's feeling rules for breast cancer survivors in terms of Rule 2 -- being "selfish" in doing what is best for them versus "selflessness;" but on the other hand *refusing* to follow Rule 3 -- feel "guilt... from the stigma associated with failing to present oneself adequately as a she-roic survivor, losing bodily integrity..." (Sulik, 2011, p. 230).

Once again invoking Gimlin's cultural work on the body, she argues that "The body might be a location of domination, but it is also a tool for resistance and agency in the construction and reconstruction of contemporary selfhood" (2002, p. 149). These ten women media interviewees who have experienced mastectomy and are now 'living flat,' have expressed in these media interviews how they have used their single-breasted or non-breasted bodies to resist breast reconstruction and prostheses. They have used their agency, their capacity to act independently from structural factors of influence such as overarching societal and cultural dominant body norms, to make their own free choices (Barker, 2004, p. 4; 2005, p. 448). They appear to have reconstructed their new normal bodies and new versions of their feminine selves as 'normal' and 'whole' women -- who just happen to be flat-chested.

### **Resisting Breast Reconstruction and Prosthetic Breasts After Mastectomy**

Existing scholarly research into women who have undergone mastectomy for a diagnosis or genetic risk of breast cancer and 'go flat' (no breast reconstruction) -- or if they have had reconstruction and decided to have their implants permanently removed (explant); who also 'live flat' without wearing prosthetic breasts in their everyday lives -- has scarcely been undertaken and is extremely limited in the academic domain. The current gap in the literature identifies this as an under-researched topical area of study. This thesis has endeavored to contribute to the knowledge base and growth of research on this topic, illuminating the need for more studies and publications to be undertaken.

Neuman believes the purpose of critical social research is "not simply to study the social world but to change it" (Neuman, 2006, p.75). According to the author, part of the critical social science (CSS) researcher's job is to "uncover myths, reveal hidden truths, and help people to change the world for themselves" (Ibid, p. 75). Sometimes this involves asking "embarrassing" questions, "exposing hypocrisy" and ultimately "... reducing illusion and ignorance ..." and as we learn, this new knowledge enables us to free ourselves from "domination ...unacknowledged constraints, dogmas and falsehoods" (Neuman, 2006, p. 75, citing Sayer, 1992:252).

The voices of the social science researchers cited, and the narratives of the women interviewed and quoted in this thesis have all contributed in some way to the generation of new knowledge about women and their post-mastectomy experiences. Cromptvoets (2006) clearly asserts that “to do nothing” as a “third choice,” needs to be regarded as a viable ‘decision’ for women undergoing mastectomy (Ibid, p. 148). She makes concrete suggestions that are manifestations of her efforts to ‘change the social worlds’ of mastectomized women: create space to nurture acceptance of the mastectomized body; encourage a higher visibility within dominant breast cancer culture of ‘non-prosthetic breast’ wearing women; advocate for and support ‘permission’ to mastectomized women to “free themselves” from the “social obligation to ‘cover up’”; develop a new framework whereby women can start to ‘see’ themselves as ‘whole’ without two breasts” (2006, pp 146, 149, 150).

Forerunners such as Lorde (1980) acted as an outspoken role model for authenticity, and in her act of doing so, made her contribution to making an empowering change for women who had experienced breast amputation. From her first post-surgical day until her death, Lorde never wore a false breast to hide her amputated one – always appearing as a one-breasted woman in public and private.

Scholar, activist and founding member of *Breast Cancer Action Montreal*, Sharon Batt (1994) believes that “A woman with cancer who confronts the world with her baldness or breastlessness has tremendous power to effect change” (Batt, 1994, p. 236). This belief speaks to the women quoted in this thesis and many others in North America and around the world who are ‘going flat,’ ‘staying flat’ and living a ‘flat positive’ life. They have taken on a role to help themselves; to use the ‘power’ of their breastlessness to change their post-mastectomy worlds. A change they see is for their betterment, to improve their quality of life and reduce their suffering, or they would not be making it or doing it. Some of their actions and behaviors stem from their own internal ideologies, others have been inspired to ‘live flat’ by others before them.

These women appear to have unknowingly taken up Cromptvoets’ challenge by seeing themselves as ‘whole – without two breasts.’ They have rebelled against the dominant body norms of body part replacement, feminine appearance that relies on being two-breasted, and healthy body appearance that also not only relies on displaying a ‘healthy’ two-breasted chest, but also ‘hiding’ the fact that they have been diagnosed and received treatment for a disease called breast cancer.

Their breastlessness also speaks to Mahalik et al. 's (2005, pp 425, 429) utilization of Downing and Roush's (1985) five-stage model to describe and define women's feminist identity development. As these 'living flat' women transition through their breast cancer trajectories, they also can be seen to be transitioning from stage 2 – Revelation: in response to their breast cancer crisis some awareness starts to creep in; they begin to question traditional gender roles and may have emotions of guilt, when they think of "how they may have contributed to their own and other women's oppression in the past." They can also be viewed as engaging in uncovering "myths" and revealing "hidden truths" (Neuman, 2006, p. 75) about what makes them 'a woman.'

When they move into stage 3 -- Embeddedness-emanation: they begin to feel feelings of connection to other women, especially women who have undergone a mastectomy. As stage 4 is approached-- Synthesis: their positive feminist identity is developed, and they are able to actively transcend traditional gender roles. For the population of 'living flat' women, this can include not doing the emotional labor it takes to keep their breast cancer and its physical signs of 'disease' hidden, in order to protect others from feeling uncomfortable.

As they move into the final stage 5 – Active commitment: they exhibit a strong commitment to positive social change that addresses societal inequalities. The women who have put themselves out in the public domain as living an actively 'flat positive' life without displaying breast mounds on their chests at any time, and live their every day lives with their 'living flat' choice, are demonstrating commitment to what they perceive as the need for social change; change that addresses the dominant breast cancer culture and its prescription that, because they are women -- only two choices post-mastectomy are viable and acceptable options: have their breasts reconstructed or wear prosthetic breasts.

Addressing Goffman's stigma theory and spoiled identity, the women who are 'living flat' appear to have enabled themselves by giving themselves and each other the support and permission they require to become more visible within the breast cancer culture (Cromptvoets, 2006). This then contributes to them not acknowledging nor allowing a sense of stigma to control their actions and behaviors regarding living flat chested without one or both breasts and refuse to hide, camouflage, or try to "pass as normal." They have decided to embrace their "new normal" as one-breasted or breastless women. They have moved on from their previous breasted bodies. It does not mean they do not mourn those bodies, just as Lorde mourned hers almost 40 years ago –

but they are committed, as Lorde was, to exhibiting their authentic selves, inside and outside their homes. This is how they have chosen to speak their truths.

Regarding Hochschild's theories of Emotion Management, Emotional Labor and Sulik's (2011, p. 230) interpretation of Hochschild's Feeling Rules for breast cancer 'survivors;' these 'flat advocate' women appear to refuse to feel or react to any emotions associated with stigma. They seem to have the ability to ignore feeling stigmatized when in a social context, even though they may be aware that some are not accepting of their socially "deviant bodies." They reject the emotion of guilt vis-à-vis "failing" to present themselves "adequately" as "she-roic" survivors. They display their flat chests as a testament to their loss of "bodily integrity" – instead of doing everything in their power to hide it (Ibid, p. 230). By refusing to engage in concealing and camouflaging behaviors, the women who 'live flat' are also refusing to take on the emotional labor that the dominant feminine norm of selflessness demands.

Invoking Swidler's cultured capacities, 'living flat' women are employing "new tools" to cope with their breast loss by embracing their flatness and refusing to allow themselves to become stigmatized. As previously discussed in this paper, our current era is of an "unsettled culture" -- one that is driven by ideologies – new ideas. New ideas lead to innovation and inventions – new ways of dealing with some times old problems. Swidler refers to these as "explicit, articulated, highly organized meaning systems" that "establish new styles or strategies of action" (Ibid, p. 278). It can be interpreted and suggested that this is what women who are 'living flat' are undertaking, as they exhibit their new breast cancer culture 'living flat' behaviors in a dominant breast cancer culture society.

### **Limitations of this Research**

These media interview data used in this thesis research were from secondary sources. They were media interviews conducted by a range of interviewers, some from academic backgrounds and others, mostly from journalism utilizing a journalistic approach. Therefore the questions were already asked, and any probing or clarifying on certain topics or specific comments made, could not be undertaken nor the expansion of answers and the like. On my part, a relationship between interviewer and interviewee as a respondent or study participant could not be established. A salient issue to consider is that of anonymity.

All the women interviewed did not have an anonymous identity as part of their media interview criteria. They used their real names and faces without disguise or anonymization. This variable could contribute to a type of subject-participant bias, which may have influenced the outcome of their comments. Perhaps because these media interviewees knew the results of their media interviews would be published, posted, filmed for documentary sales or uploaded in the public domain in multimedia, an element of self censorship such as behaving or saying things that they thought the interviewer wanted or expected them to do or say could have been at play during the media interview process. Another constraint to achieving a wide range of media interview data results and as close to authentic responses is the fact that the data used in my study went through editing processes by the writer, publisher, filmmaker, and videographer. All these points underscore the need for primary interview data obtained from face-to-face interviews, within the scope of a professionally executed, academic research study.

It was not possible to ask these media interviewees any direct questions that deal with specific dominant body norms, and also stigma that they may have experienced, and how they navigate having a non-dominant body image in the public domains of society.

### **Potential Questions to be used in Future Face-to-Face Interviews**

There are potentially numerous and varied other motivations for rejecting breast reconstruction and the wearing of prosthetic breasts, than the ones uncovered in my thesis study which warrant further, close investigation in future studies. Given it was not possible to ask these media interviewees any direct questions during an academic research study that also guarantees their anonymity, many potential questions to be used in future research could be considered, that could assist in identifying some different motivators. Other lived experience issues related to ‘living flat’ also warrant further study. For example: Have they received, and if so how do they cope with, dominant breast cancer cultural norm pressure to hide their flat chests or one-breastedness under artificial breasts, clothing or accessories such as scarves and jewelry? What kinds of comments and opinions have been verbalized to them in private and in public, regarding their decision to ‘go flat’ and ‘live flat’? How do they cope with these comments and experiences, when they are negative and include pressure to conform? Have family members, spouses, partners, children, friends, colleagues, health care professionals or strangers put social pressure on them to conform to a post-mastectomy cultural dichotomy of either having breast



reconstruction or wearing prosthetic breasts? If yes, how has this pressure been manifested? Have any relationships with spouses, partners, or others ended due to conflict from their decision to ‘go flat’ and ‘live flat’? If they are dating, how do they navigate, and what are their experiences with dating? Have they ever, at some point decided to end ‘living flat’ and looked into breast reconstruction, or started to wear artificial breasts in specific milieus, when in certain circumstances or when attending special events and the like? If so, what were their motivations behind making such a decision? Have they ever had adverse employment or workplace issues or lost their job as a result of their choice to ‘live flat’? Do they have any other lived experiences they would like to share?

### **Suggestions for Further Research**

It is my aspiration that this thesis will make an original contribution to an area of social research that has received limited to no scholarly attention to date. Judging from the dearth of focused research on the topic of agency and choice related to ‘going flat’ and ‘living flat,’ my goal is for this thesis to inspire others to study this under-researched topic. The women who ‘live flat’ appear to be an underserved and sometimes isolated group, except when they happen to find and access social media advocacy and support groups or websites. With research comes publication and the potential for a growing corpus of work that inspires strong networks, support groups, academic conferences, multi-media such as documentaries, theatre, music, visual arts, and dance as varied dissemination-communication of an academically researched and validated message.

Not only is there the hope that future research will give a greater voice to the members of this mostly unknown, silent, hidden, non-conforming, non-dominant breast cancer culture. It is equally envisioned that it will carry further into questioning whether ‘living flat’ has the potential of becoming a more significant body movement, by and for women. One where the decision-making involved regarding ‘living flat,’ and what happens to their breasts and chests post-mastectomy, results in, ‘living a flat-positive life’ being validated as a ‘third choice’ that then becomes normalized and accepted by all domains of society.

As previously discussed, American plastic surgeons Offodile II and Lee’s (2018) findings suggest several directions for future research regarding breast cancer surgery and breast reconstruction. They identified several priorities that need a clear research focus. A major one is

reducing morbidity (medical problems caused by the treatment) – along with the risk of short and long term complications and changes in physical functioning. Another priority should be given to developing and implementing previously proven shared decision-making interventions. These could include patient decision aids and decision coaching – as they greatly assist in improving the quality of decisions. One example of a recently available shared decision-making App downloadable to cellular phones claims to adhere to the philosophy that “ Shared decision-making occurs when the health care professional and patient work together to make a treatment decision that is best for the patient. It includes information on a ‘going flat’ option. The best decision takes into account evidence-based information about treatment options, the physician’s knowledge, and the patient’s preferences and values” (breastadvocateapp.com, 2019). Policy mechanisms at federal and state (provincial) levels would promote positive clinician behavior change regarding surgeons being mandated to receive training in how to elicit patient preferences relative to reconstruction – without explicitly doing this, a surgeon is unlikely to know what the patient values. These types of policy changes could also be encompassed in state (provincial) legislation – citing the Washington State 2007 example that acknowledged shared decision making as a critical component of the informed consent process (Offodile II & Lee, 2018).

The area regarding ‘flat closure’ procedures desired by some women having breast cancer surgery also demonstrates a need for rigorous research. Women who ‘go flat’ and ‘live flat’ in a ‘flat positive’ manner do not want plastic surgeons out of their lives. On the contrary, they continue to embrace their expertise and talent but in ways specific to their own needs. According to the organization *Flat Closure Now*, women who choose to ‘live flat’ want a smooth and aesthetic ‘flat closure’ executed by plastic surgeons, breast surgeons or general surgeons who are versed and trained in this patient-driven specialized post-mastectomy procedure. Flat Closure Now.org states that “A flat closure after a mastectomy means the surgeon removes not only breast tissue but also excess skin and tissue to achieve a smooth, flat result” (Flat Closure Now.org, 2019).

Referring back to the overarching processes of informed consent, patient decision-making and endeavoring to improve their overall quality; I am suggesting that a last, but vital suggestion for further research involves the area of applied sociology. In the medical context investigating how sociologists can take their place as members of medical policy and procedure teams. How they can become involved in creating and implementing breast reconstruction decision aids and

decision coaching – and thus contribute to improving the quality of patient breast reconstruction decisions. Researching the role of sociologists consulting and collaborating in medical and other domains is an essential step toward employing the previous and current work of sociologists, as applied research within a variety of sectors and organizations (Rapid Context.com, 2019), including all that encompass those dealing with the body, body image, and stigma.

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